AGING WITH LONG-TERM PHYSICAL DISABILTY:

THE ROLE OF SECONDARY CONDITIONS

Heather J. Moulton

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ABSTRACT

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Objectives: The purpose of this study is to advance the understanding of secondary conditions experienced by persons aging with the long-term disabilities of polio and rheumatoid arthritis and the consequences of these declines in health and function on disability bed days. Additionally, it explores the effects of the timing and severity of onset of disability characteristics on the frequency and consequences of secondary conditions. A life course conceptual framework with the Institute of Medicine's model of disablement is used to frame and anchor disability and life events.

Methods: In-depth structured in-home interviews were conducted on 216 individuals with polio and 186 individuals with rheumatoid arthritis. They consisted of objective and subjective self-reports of current status and prior condition. The survey was a regional cross-sectional, group comparison design with a cross-sequential sampling and data analytic framework. Scale development for data reduction was utilized to obtain parsimonious measures for the models. Linear regression was then performed to test the models for three outcome variables (number of chronic secondary conditions, increases in functional limitations and number of disability bed days in six months) in a theorized order for the polio and RA samples individually.

Results: There was partial support for within-sample hypotheses for both polio and rheumatoid arthritis regarding interrelationships and disability bed days in past six months. No significant differences were found across subsamples for the effects of timing and severity of

onset of disability characteristics, predicting chronic secondary conditions, predicting increase in functional limitations, and the number of disability bed days in six months. Similarities were found between the two samples when examining subgroup predictors on the three outcomes above. Chronic secondary conditions predicted ($p<.05$ for both subsamples) increase in functional limitations and increase in mobility was a significant predictor ($p<.001$ for both subsamples) of increase in functional limitations.

Discussion: There were limited findings for these data. Judgment must be withheld with respect to the hypotheses. The analyses did not yield enough predictive strength to make comparisons possible across subsamples. Likewise, in examining similarities, only general, descriptive statements could be made. The subjective nature of disability is an immense challenge in cross disability research for comparability within disabilities and across disabilities.

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DEDICATION

In memory of Katherine E. Hurd Winchester, my maternal grandmother, who was still sharp as a tack when she passed away at the age of 95 in Kennebunk, Maine. I will always remember laughing so hard that I would cry at her stories of the (mis)adventures of picking "those damn blueberries" after church in the summer when she was a young girl. Her spirit instilled in me a deep respect for aging and what it has to offer, not what it has to take away.

To my twin sons, Thomson and Kelton, who despite feeling overlooked at times towards this dissertation's completion, gave me hugs, love and encouragement. I cherish you.

I. INTRODUCTION

Advancements in medicine, health care, rehabilitation and public health in our society have contributed to an increase in average life expectancy. People are aging with long-term physical disability acquired earlier in life, and older persons who develop disability are living longer with their disabilities and are aging into disability. Life expectancy has increased. Those who live to age 65 have an average life expectancy of an additional 19.2 years (20.4 years for females; 17.8 years for males) (Administration on Aging, 2011). Additionally, the number of persons aged 45-64 who will reach 65 within the next 20 years increased by 33% (Administration on Aging, 2011). In 2010, of the 303.9 million of the non-institutionalized population, approximately 56.7 million (18.7%) people had a disability and approximately 38.3 million (12.6%) had a severe disability (Brault, 2012). The number of those disabled increased by 2.2 million from 54.4 million. Approximately 12.3 million people (4.4%) aged 6 years and older required assistance with at least one basic activity of daily living (BADL) or instrumental activity of daily living (IADL) (Brault, 2012).

In previous eras, individuals with long-term moderate to severe disability did not survive long enough to be candidates for aging. Now they are experiencing similar benefits in longevity as the rest of the population, yet their medical, psychological and social needs are less understood. With this comes the paradox of longevity. There are increased risks of new health-related problems that come with longer life. For these persons, the timing of these increased risks occurs earlier than is seen in the general population. This premature onset has several implications: health care resource implications, but also psychological and social implications. A population level (N=10,898) analysis (McColl, 2005) utilizing the Canadian National Population Health Survey compared disabled and non-disabled adults, aged 20 - 64, on health

and disability variables. The health and disability variables were not reported by age groupings, however, disability status by age was. When four categories comprising persons 45 – 64 years old are combined, the percentage of those nondisabled in the sample is the 34% compared to 54% of those disabled. With respect to chronic conditions, 49% of the non-disabled had no chronic condition while 100% of the disabled population had at least one chronic condition. Ten percent of those who were nondisabled had three or more chronic conditions as compared to 47% of those with a disability. Chronic conditions were not reported by age, but for the entire sample. Despite the fact that these data were from Canada, it nonetheless highlights the differences in the timing of the onset of increased disability conditions.

Health for any given person is not static (Rimmer, 1999). A person may be found on either end of the health spectrum (from low to high) at any given time depending upon any number of factors. Rimmer (1999) uses the example of a person who at 40 has good health promotion practices and is at the high end of health but is then diagnosed with cancer. During chemotherapy this person would be considered at the low end of the health spectrum. Once treatment is finished, however, and healthy practices resume, health can shift back to the higher end of the spectrum. Just as persons without long-term disability move in and out of health during their lives, so do persons with disability (Marge, 1999; Rimmer, 1999).

However, individuals aging with long-term physical disabilities differ from the population at large in that their shifts in health status typically occur at younger ages and are preceded by or co-occur with significant increases in impairment related to the underlying disability and with declines in functioning. Post-polio syndrome provides a perfect example of moving in and out of health. Many persons who experienced polio "recovered" to move on to lead healthy productive lives only to start experiencing a decline in their health later in their lives

that is due to their primary disability. If the post-polio syndrome is managed well, health may be maximized within the context of their disability. Rimmer, however, discusses disability only within the context of health promotion and does not make the distinction between health, impairment and function. Simply stated, disability is the result of impairment and functional limitations originating from a primary disease or pathological process (Nagi, 1965) and these are not static. For instance, an individual with Rheumatoid Arthritis (RA) has periods of disease fluctuation that can result in an increase in impairment and often a decline in function, but can also experience a period of recovery where impairment declines and function improves. Yet, despite this improvement, the overall trend of these individuals' health declines. This decline happens earlier thus putting them at risk earlier for the leading causes of death. Rimmer (1999) also notes that the difference in the health shifts between those who have a long-term disability and others is that those with disability start at a lower position on the health spectrum and adds that secondary conditions intersecting with the primary disability is a primary reason for this. Additionally, those with disability are at higher risk for secondary conditions precisely because of their primary disability (Marge, 1999).

Campbell and Sheets (1998) compared a sample (N=555) of three age-matched cohorts who were aging with disability (post-polio, rheumatoid arthritis and stroke) to a national sample (Adams and Marano, 1995) and found that persons with long-term disabilities reported higher rates of almost all chronic conditions compared to same-age cohorts from the general population. Their data suggest that persons with early-onset of physical disabilities experience secondary health conditions which may put them at risk for "accelerated aging." They show that compared to same-age cohorts from the general population, persons with long-term disabilities report higher rates of almost all chronic conditions. This pattern is most pronounced in the 45 - 64 year

old cohort, where rates are two to ten times greater. They conclude that public health implications include providing health care professionals and disability advocates with information that can be useful in identifying low and high-risk groups, and in targeting prevention efforts more effectively. The inclusion of "Disability and Secondary Conditions" as a Focus Area in *Healthy People 2010* (U.S. Department of Health and Human Services, 2000) indicated the emerging importance of preventing secondary conditions among persons with disabilities of all ages. However, in *Healthy People 2020* (NCHS, 2012), the Disability and Secondary Conditions Focus Area was expanded to increase the emphasis on health determinants and address a broader range of objectives. The Focus Area's name was changed to "Disability and Health," thus diminishing the importance secondary conditions.

Policy initiatives such as the New Freedom Initiative (NFI) (2001) and the implementation of the Olmstead Decision (Olmstead v. L.C., 527 U.S. 581 [1999]) by the Olmstead Executive Order (13217, June 18, 2001) have increased attention to disability. These two initiatives have placed tremendous emphasis on independent living and community integration, both public health related themes. The American with Disabilities Act (ADA, 1990) was referenced in both the NFI and the Olmstead Decision. The NFI's key components are: increasing access to assistive and universally designed technology; expanding opportunities for those with disability to access to education; promoting full access to community life; increasing integration into the workforce; increasing access to transportation; and promoting homeownership. The Olmstead Decision by the U.S. Supreme Court compelled the federal government to fully enforce Title II of the ADA (U.S. Department of Justice, 1990; U.S. Department of Justice, http://www.ada.gov/olmstead/q&a_olmstead.pdf). This meant that public

entities must avoid disability-based discrimination and provide to persons with disabilities community-based services if the services are appropriate and can be reasonably accommodated.

The most recent legislation to positively impact individuals with disabilities is the Patient Protection and Affordable Care Act (PPACA) signed into office on March 23rd of 2010 by President Obama (PPACA, 2010). It mandates and provides incentives to: 1) expand home or community-based care and directly cites the Olmstead Decision; 2) remove barriers and improve access to wellness for persons with disabilities; 3) eliminate discrimination against individuals because of age, disabilities or life expectancy with regard to coverage or reimbursement; and develop a healthcare workforce versed in cultural competency, prevention and public health. On a more macro level, the PPACA includes programs that balances types of care, establishes a single point of entry, and improves coordination and transitions between care settings, all of which greatly benefit individuals with disabilities, as well as all users (Reinhard, Kassner and Houser, 2011).

A. Statement of the Problem

Because persons with disability have been under represented in national surveys and the data that have been collected across surveys are not comparable, it has been difficult estimating the number of persons aging with long-term disability (Campbell, Sheets and Strong, 1999). Additionally, better questions, such as age at onset and duration of primary disability, need to be asked. It is therefore difficult to estimate the costs to individuals and to society that are associated with secondary health conditions. There are direct and indirect economic costs such as medical dollars associated with the need for increased health care services, the inability for persons to engage in gainful employment, and the need for increased level of assistance. There are also social costs such as the decrease of quality of life for individuals and their families.

Identifying risk factors for secondary health conditions will assist in determining how best to reduce the overall risk for age-related chronic conditions and thus reduce economic costs and increase quality of life for individuals aging with long-term disability.

Before risk factors can be adequately assessed, secondary conditions have to be better defined and understood. Verbrugge, Merrill and Liu (1999) discuss the continually expanding survey questions used to measure disability and call for a global disability item similar to morbidity's self-rated health in an effort to be parsimonious in measuring disability. Not having a widely accepted definition limits the ability of researchers to compare results and compile data sets for techniques such as meta-analysis. Determining key indicators of the components that comprise secondary conditions will also assist in creating more parsimonious models even if one global measure cannot be defined.

Past analyses using disability populations have utilized univariate and bivariate approaches. The literature has largely focused on conceptual refinement. Interrelationships of secondary conditions have not been examined with respect to how they work together to effect some policy related variable or health outcome.

B. Study Goals

This study is a methodological investigation to advance the understanding of interrelationships among hypothesized declines in health and function experienced by persons aging with the long-term disabilities of polio and rheumatoid arthritis. It will explore the effects of the trajectory of unique disability characteristics on the frequency and consequences of declines in health and function, examine the consequences of these declines in health and function on a health policy outcome, and finally compare distinctive disability characteristics between polio and rheumatoid arthritis on the trajectories of health and decline in function.

Independent of any hypotheses is another objective, which is to develop and test measurement models. Multiple indicator latent variables are constructed the major components of the chronic secondary conditions construct for persons aging with disability: 1) onset of new or increased disability-related symptoms; 2) onset of new declines in functional status; and 3) onset of chronic secondary conditions. The interrelationships among these measures are then examined.

Four goals are presented to address the measurement and understanding of secondary conditions across polio and rheumatoid arthritis.

1. Advance the understanding of interrelationships among the components of secondary conditions for polio and rheumatoid arthritis;
2. Explore how the unique disability characteristics of polio and rheumatoid arthritis with respect to severity at onset and temporal disability may be linked to differences in secondary conditions;
3. Advance the understanding of the consequences of secondary conditions on disability bed days for individuals aging with long-term disabilities of polio and rheumatoid arthritis; and
4. Compare potential subgroup differences between individuals aging with polio and rheumatoid arthritis in central indicators of each secondary condition component.

II. LITERATURE REVIEW

A. Disablement

Disablement is a process of change. Understanding disability, its complexities, and its impact at the individual and societal levels is a challenge. Since Nagi (1965) first proposed his framework of disability in an effort to define and conceptualize disability, it has endured several decades and is the basis for the models described below. The concept of disablement describes a pathway with several domains from pathology to disability. Although these labels have evolved and in some cases, have been changed considerably, Nagi's basic model has endured. This pathway is the result of a process that involves biological, environmental (social and physical), and lifestyle and behavior risk factors. Each point in the progression along the pathway can be influenced by these risk factors. The extent of disability and how it is experienced is the result of susceptibility due to these risk factors.

The basis for the model presented in this dissertation is that of Nagi's (1965) and the IOM's (1991). However, a review of the history of other primary models is useful as it illustrates the difficulties of developing a model that meets, at times, competing needs.

1. The Nagi Model & The Institute of Medicine

The concepts in Nagi's (1965) scheme, active pathology, impairment, functional limitation, and disability were similar to the ICIDH, however, there was no parallel to the ICIDH "handicap" concept because of Nagi's sociomedical framework (Verbrugge and Jette, 1994). Verbrugge and Jette (1994) emphasize the intellectual scope and adaptability of Nagi's scheme. This scheme consisted of 1) active pathology, the origin and defined as an interference of normal processes resulting from infection, trauma, metabolic imbalance, degenerative disease or other etiology and the concomitant efforts to normalize; 2) impairment defined as anatomical,

physiological, mental, or emotional abnormalities or loss; 3) functional limitation defined as limitation in performance of the individual due to the effects of impairment; and 4) disability defined as limitation in performance of socially defined roles and tasks within a sociocultural and physical environment. The IOM (1991) adopted the Nagi model with revisions by Nagi himself (1991), adding risk factors that occur both within the individual, and in the physical and social environment. It was again revised (IOM, 1997) in 1997 to expand on environmental factors and add quality of life.

2. International Classification of Impairments, Disease, and Handicaps

The International Classification if Impairments, Disease, and Handicaps (ICIDH, 1980) was a taxonomy of disease impacts with three central concepts, impairment, disability, and handicap, that were tied to the International Classification of Diseases (ICD, 1986) used in medicine and health statistics. Disease was the origin of the model. Three levels of performance were then described that were conceptually distinct. Impairment corresponded to organ-level performance and defined as loss or abnormality of psychological, physiological, or anatomical structure or function. Disability corresponded to person-level performance and was defined as a restriction of lack of ability to perform an activity in a normal manner. Handicap was defined as disadvantage due to impairment or disability that limits or prevents fulfillment of a person's normal role (depending upon age, sex, sociocultural factors) and corresponded to societal level performance. Controversy arose with the use of "handicap" and also neglecting to consider environmental factors (Whiteneck, 2007). As a result, a modified model, International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001) was introduced and is discussed below.

3. The Disablement Process

Verbrugge and Jette, (1994) described "The Disablement Process," a sociomedical model of disability built on Nagi's (1965) conceptual scheme of disability and to a lesser extent, the International Classification if Impairments, Disease, and Handicaps (ICIDH, 1980). The components of Verbrugge and Jette 's disablement process expanded upon Nagi's model by accounting for behaviors that increase risk factors or buffers to functional limitations and disability. These factors are extra-individual and intra-individual. Extra-individual factors include medical care and rehabilitation; medications and other therapeutic regimens (biofeedback/meditation, etc.); external supports; and built, physical, and social environment. The intra-individual factors include lifestyle and behavior changes (overt changes to alter disease activity); psychosocial attributes and coping (prayer, peer support groups, locus of control, etc.); and activity accommodations.

An important aspect of this model is the recognition that these factors may operate along the disablement trajectory at any point. Additionally, it allows for other outcomes such as quality of life (placed after disability), and "feedback loops" for secondary conditions and dysfunctions within a disablement process or new disablement processes. Verbrugge and Jette (1994) discuss the actuality that disability is a gap between person and environment. Furthermore, a key element of the disablement process is the malleability of demand and reducing that demand by activity accommodations, environmental modifications, psychosocial coping, and external supports.

4. The International Classification of Function, Disease, and Health

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International Classification if Impairments, Disease, and Handicaps (ICIDH, 1980). The components of Verbrugge and Jette ‘s disablement process expanded upon Nagi’s model by accounting for behaviors that increase risk factors or buffers to functional limitations and disability. These factors are extra-individual and intra-individual. Extra-individual factors include medical care and rehabilitation; medications and other therapeutic regimens (biofeedback/meditation, etc.); external supports; and built, physical, and social environment. The intra-individual factors include lifestyle and behavior changes (overt changes to alter disease activity); psychosocial attributes and coping (prayer, peer support groups, locus of control, etc.); and activity accommodations.

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B. Aging with Disability

Aging is a lifelong developmental process that starts at birth. For most aspects of aging, chronological age is a poor measure (Sheets, 2010). Disability may occur at any point along the developmental aging process. Those who are disabled experience aging with disability, while those who are aging experience disability with aging. Aging with disability is increasingly recognized as an important and challenging area to study. Until recently, individuals aging with a disability have not enjoyed the same life expectancy as their non-disabled peers. Advances in medicine and rehabilitation have made it possible for many with long-term disabilities to live into later life. As a result, the onset of secondary conditions (complications to the primary disability) is experienced earlier than those who are aging into disability and contributes to an accelerated aging (Campbell, 1997).

Persons with lifelong disability do not always have the same opportunities with respect to skills, activities and life experiences (Verbrugge and Jette, 1994) as those who are experiencing disability with aging. The disability with aging cohort experience disablement gradually and can work to restore capabilities they once had (Verbrugge and Jette, 1994). Thus, the individual aging with a life-long disability "looks" very different from the person who has developed disability with aging.

While there is some overlap between these two disability groups, they are very different. Their languages and behaviors differ. Age composition, professional background of its members and the type of services utilized characterizes the disability community (Campbell, 1997). Those who are in the disability with aging cohort are 65 years old and older, are in the aging network and have a more recent onset of disability. Age at onset (birth to young middle-age vs. mid to later life), cause of disability (congenital & acute disease/injury vs. chronic health conditions),

group identification (disability culture vs. ill-health), consumer role (advocates vs. patients/recipients) and professionals involved in service delivery all differ (Campbell, 1997).

Some collaboration between the two groups has existed in the scientific community, however, in the discipline of social service, disability and aging have been distinct (Verbrugge and Yang, 2002). The two groups have been shaped historically by policy. Even as far back as the revolutionary war the government paid soldiers disability-related and old-age pensions (Putnam, 2007). Restricted perceptions have existed since this time. Disability programs are focused on education, employment and housing, where aging programs focus on social well-being and disease management (Verbrugge and Yang, 2002). Campbell (1997) contrasts the policies that helped to shape these two groups. The efforts of the disability community's political activism resulted in the amendment to the Rehabilitation Act in 1978 and passage of the Americans with Disabilities Act of 1990, which set standards for public and workplace accessibility, but no way to implement them. In the aging network, legislative action created the area agencies on aging to expand the social service programs under the Older American's Act of 1965.

C. Secondary Conditions

Secondary conditions in persons aging with long-term disability constitute negative and costly consequences of the disablement process, which through interventions and treatment, can be prevented or reduced (Campbell, Sheets, Rhaney and Moulton, 1999). They can compromise function that can lead to a loss of independence, undermine economic self-sufficiency, contribute to "accelerated aging," and increase utilization of health and long-term care services. What defines a primary condition or a secondary condition or a chronic condition or a comorbid condition can depend upon one's disciplinary perspective.

The concept of secondary conditions is a complex multidimensional construct. Marge (1988) was the first to name and define "secondary disabilities." The Institute of Medicine (Pope and Tarlov, 1991) cited Marge's work, however, it was reframed as "secondary conditions." Currently, the term "secondary conditions" has no operational definition which functions as a gold standard (Campbell, Sheets and Strong, 1999; Wilber, Mitra, Walker, Allen, Meyers and Tupper, 2002; Nosek, Hughes, Petersen et al, 2006). In the Institute of Medicine's (Pope and Tarlov, 1991) model, secondary conditions are defined as "a condition that is causally related to a disabling condition (i.e., occurs as a result of the primary disabling condition) and that can be either a pathology, an impairment, a functional limitation, or an additional disability"....and "would not occur in the absence of the primary condition (p.214)." This causal relationship that is discussed can be either direct or indirect. In Healthy People 2010 (U.S. Department of Health and Human Services, 2000) secondary conditions is defined more broadly as "medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences (p. 6-3). "

The above definitions represent just two of the various definitions for secondary conditions that can be found in the disability and public health literature. Other definitions include factors such as complications and injuries that occur after the onset of the primary disability, new and/or increased symptoms, impairments, functional limitations, limitations in ADLs and IADLs, and limitations in social roles (Campbell, 1999). Wilber et al. (2002) cite the use of even broader definitions such as health-related economic consequences for the individuals and members of their families. Campbell, Sheets, and Strong (1999) discuss, as a definition of secondary conditions found in the literature, the inclusion of age-related chronic conditions (also known as co-morbidities) that affect the general aging population, but may occur earlier and

more frequently for persons with physical disabilities because of a narrower margin of health (DeJong and Hughes, 1982). Presently, the term secondary condition lacks clarity. More research is needed to elucidate the causes and consequences of secondary conditions with respect to disablement (Jette, 2006). Secondary conditions for this present analysis will include symptoms, chronic conditions and functional limitations.

1. Symptoms

Different disabilities have different symptoms; however, pain, fatigue and muscle weakness cuts across almost all disabilities. They are three of the most common symptoms experienced by persons aging with disability and should not be confused with normal aging. These symptoms, if not addressed, can result in further disability. Further and specific discussion with regard to these three universal symptoms can be found in the polio and rheumatoid arthritis sections.

Disability has been found to be a strong predictor of chronic pain (Kinne, 2004) and requires examination to identify its cause in an effort to preserve function and to prevent or delay further decline. Fatigue is characterized by tiredness, loss of energy and inability to carryout everyday activities. It is three times more frequent in persons aging with disability than with the general population (Thompson, 2004). Extreme fatigue and pain have been found to have an independent relationship to fair to poor health (Kinne, 2004). Cook, Molten and Jensen (2011) found in their study of persons aging with spinal cord injury, post-polio syndrome, multiple sclerosis, and muscular dystrophy, that the risk of fatigue is greater than those without a disability and it also increases with age compared to normative values. Fatigue can impact all aspects of one's life. It can interfere in functional activities, sleep, and contribute to depression for example. It is often not given credence by health care professionals because of confounding

variables such as lack of sleep and depression. Work simplification and energy conservation techniques can help to ameliorate fatigue.

Muscle weakness is characterized by diminished physical or muscle strength. It can be associated with muscle and joint pain, general deconditioning and sarcopenia. There is a feeling that extra effort is required to perform activities. Depending upon where the muscle weakness is, throughout the body or isolated to specific muscles, there are implications for limitations. Upper extremity weakness can result in the loss of one's ability to propel a wheelchair or perform activities of daily living such as dressing, bathing, and meal preparation. Lower extremity weakness can interfere in ambulatory activities. Exercise is valuable in promoting and maximizing overall health, but must be approached conservatively as too much exercise can be counterproductive and cause injury.

2. Chronic Conditions

Turk (2006) outlines the history of secondary conditions from concept to practice. She identifies the key dimensions of secondary conditions and then places secondary conditions using the taxonomies of disabilities from rehabilitation science and clinical practice. These are "primary conditions," "associated conditions," "comorbidities," "aging" and "health." "Treatment complications" is another category added (Field and Jette, 2007) to this list. Primary conditions are the fundamental sources of disability. Associated conditions are aspects of the pathology of the primary condition that are expected to occur. Turk (2006) uses as example the primary condition of cerebral palsy that has several expected (associated) conditions that may or may not occur and to varying degrees: seizures, spasticity (an aspect of upper motor neuron impairment) and cognitive impairment. Comorbidities are health conditions that are independent of the primary condition. Aging occurs whether there is a primary condition or not, however,

problems associated with accelerated aging, such as early-onset deconditioning, can be considered secondary conditions (Turk, 2006). Similar to Rimmer (1999), Turk defines health as a continuum that is not the absence of impairment or disease, but is dependent upon management of chronic disease, maintaining function and preventing secondary conditions. Treatment complications result from treatment of the condition and not the condition itself and can be preventable (Field and Jette, 2007). An example would be a side effect of a medication used to treat the primary condition.

In the medical literature, treatment complications have been identified as comorbidites (NRAS, 2012). With respect to rheumatoid arthritis, two types of comorbidity are defined: those resulting directly from the disease and those resulting indirectly from treatments (NRAS, 2012). In a review of comorbidity measurement, de Groot, Beckerman, Lankhorst and Bouter (2003) acknowledge that there is no consensus with regard to the definition of comorbidity, but stipulate when an index (or primary) disease is required for conducting research. In research on multimorbidity no index disease is used, however, comorbidity research requires that an index disease be used. They note that comorbidity can be either the consequence or cause of a primary disease and they may also share the same risk factors.

There is a general agreement that the common denominator across definitions is that secondary conditions occur after the onset of the primary disability and are directly or indirectly related to it (Ravesloot, Seekins & Walsh, 1997; Campbell, Sheets and Strong, 1999; Kinne, Patrick and Lochner Doyle, 2004; Turk, 2006; Rasch, Magder, Hochberg et al., 2008). Additionally, agreement exists with regard to factors that cause secondary conditions: overuse of a neuromuscular system weakened from the primary condition (Turk, Overeynder and Janicki, 1995); under or misuse of the neuromuscular system due to problems with gait, immobility or

deconditioning for example (Krause, 1996); complications from the primary condition (Treischmann, 1987); poor coping strategies and lifestyle behaviors such as alcohol abuse, poor nutrition, smoking, etc.; and environmental and attitudinal barriers that result in limiting access to health promotion and social participation (Brandt and Pope, 1997). Research by Kinne (2008) and Nosek, Hughes, Petersen et al (2006) illustrates the differences in how secondary conditions are defined, nonetheless, they each provide evidence of the magnitude of these conditions. Kinne follows the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) model and delineates between types of secondary conditions: secondary medical problems, secondary impairments and secondary participation limitations. Nosek, Hughes, Peterson et al eliminated conditions that resulted from or reflected their subjects' interaction with their environment and focused on health outcomes.

A conceptual model of secondary conditions that incorporates the ICF is proposed by Rimmer, Chen and Hsieh (2011) for the purposes of promoting higher-quality research in secondary condition prevention among rehabilitation and public health researchers. Before addressing their conceptual model, they propose a hierarchical set of criteria for defining a secondary condition and created a decision-making algorithm for identifying them. They then present a conceptual model of the onset, course, and outcomes of secondary conditions in people with disabilities. As complex as their overall model is, their algorithm for identifying secondary conditions and corresponding management spectrum (p. 1732), if adopted by enough researchers, would go a long way in uniformly identifying secondary conditions.

Ravesloot, Seekins and Walsh (1997) performed a structural analysis to determine how secondary conditions might group and if factors are related to various primary impairments. They found that primary impairments did not predicted specific factors of secondary conditions,

however, certain secondary conditions were evident across a variety of impairments. Kinne (2004), in a population based cross-sectional study, found that secondary conditions were common among adults with disabilities, and that disability was the strongest predictor of pain, weight problems, fatigue, problems getting around, falls and other injuries, sleep problems, muscle spasms, and bowel and bladder problems. Nosek, Hughes, Peterson, Taylor et al (2006) found in a cross-sectional study of women who were primarily ethnic minorities, that secondary conditions in women with physical disabilities were more problematic than previously reported in the literature.

Chronic conditions is a term used primarily in medicine and health services research for the purposes of describing trends (Martin, Freedman, Schoeni and Andreski, 2010), patterns of utilization (Schneider, O'Donnell and Dean, 2009) and estimating chronic conditions (Freid, Bernstein and Bush, 2012), managing and preventing chronic disease (Martin, Freedman, Schoeni and Andreski, 2010), predicting health care needs (Wolff, Starfield and Anderson, 2002) and costs (Wolff, Starfield and Anderson, 2002; Schneider, O'Donnell and Dean, 2009; Lewin Group, 2010), and measuring quality of care (Iezzoni, 2010). Chronic conditions are often analyzed with functional limitations for the impact it has at an individual as well as a societal level. It can be defined as comorbidity based on diagnostic codes (Wolff, Starfield and Anderson, 2002). It can also be defined simply as a condition that lasts more than12 months and results in functional limitations or requires ongoing care (Lewin Group, 2010) or as health problem that persists over time without cure and caused by an underlying disease (Iezzoni, 2010). Iezzoni (2010) provides a thorough discussion of the definitions of chronic conditions and disability. She identifies disease and disability as distinct concepts that often coexist. Disease frequently contributes to disability and disability can cause secondary conditions or new diseases. This is

illustrated by her example of osteoarthritis impairing ambulation as a disease contributing to disability and spinal cord injury contributing to pressure ulcers as a disability causing secondary conditions or new diseases.

The term multiple chronic conditions (MCCs) is gaining traction among health care professionals and researchers as it recognizes that increasing numbers of the U.S. population have two or more chronic conditions (Iezzoni, 2010; Freid, Bernstein and Bush, 2012). From 2000 – 2010, Freid, Bernstein and Bush (2012) found an increase in the percentage of adults who had two or more of nine selected chronic conditions in both the 45 – 64 and 65+ cohorts. These findings held across gender, all racial and ethnic groups studied and most income groups. There has not been an explicit recognition that multiple chronic conditions pose an important additional complexity to our healthcare system (Parekh, Goodman, Gordon, Koh et al., 2011). The National Quality Forum's final report (2012) for the MCCs Measurement Framework considered the difficulties of how MCCs are defined. A broad definition cited is the presence of two or more conditions. The difficulty with this is that it potentially captures too large a population and does not consider complexity and interactions of MCCs, e.g., having chronic sinusitis and osteoarthritis of the knee versus rheumatoid arthritis and diabetes. The report also cites the Agency for Healthcare Research and Quality's (AHRQ) definition as addressing the complexities and interactions, yet it leaves out health status considerations such as function and quality of life. As a result of these incomplete definitions, the MCCs Steering Committee has defined MCCs as "having two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life and that require complex healthcare management, decision-making, or coordination (p. 7-8)." This definition, gives substance to the complexity that MCCs bring to healthcare.

The move from a single disease focus to a multiple disease focus is an inevitable one. Treating illnesses individually ignores the synergistic impact (Vogeli, Shields, Lee, Gibson et al., 2007) of MCCs. Furthermore, treatment guideline conflicts can easily arise resulting in potential harm (PFCD, 2013). Patients are managed with MCCs in an acute care delivery and financing system (Thorpe, 2013), yet there is little health policy research with regard to the complex challenges that these patients present (PFCD, 2013; NQF, 2012; PCORI, 2013). These challenges exist across the spectrum of health care and involve (Thorpe, 2013): patient empowerment; evidence-based management including pay-for-performance; and effective models of care that encompass prevention, self-management, caregiving and care coordination, and workforce training. A further challenge is to recognize that whether they are named secondary conditions, chronic conditions, comorbidities or secondary chronic conditions, on a practical level, secondary chronic conditions are becoming more common across the entire lifespan. It is important not to lose sight that there is an increasingly younger population that has a long-term primary disability that they will be aging with. Not only will they have secondary chronic conditions, they will develop additional conditions that they will have to live with earlier than they would have to without their primary disability. Thus as younger populations are living longer with disabilities that were once not survivable into an advanced age. The healthcare system needs to treat people with long-term chronic disability at all ages with the same basic framework that will take into consideration variations in age and disability.

3. Functional Limitations and Functional Disability

Functional limitations are restrictions in an individual's ability to perform tasks or activities. Following the IOM/Nagi disablement model, functional limitations are the results of impairment and in turn are a measure of disability. It is important to note that not all impairment

leads to functional limitations and mild functional limitations may not lead to disability. In research, functional limitations have traditionally been measured by three components: basic activities of daily living (BADL), instrumental activities of daily living (IADL), and mobility. Items included in each component can vary, but are generally similar from study to study. There is disagreement in the literature as to whether these measures are hierarchically related (Spector and Fleishman, 1998; Thomas, Rockwood and McDowell, 1998).

BADL items are eating, dressing, bathing, transferring (from bed to chair), toileting, and grooming. IADL items can include meal preparation, shopping, chores/light housework, money management, medication management, and telephone use. Mobility, the ability to move from one point to another independently, is used as a component or can be placed under the BADL component. Examples (Guralnik, 2011) of items that can assess mobility are unable to walk ½ mile or climb stairs (higher mobility disability), or unable to walk across a small room without help (severe mobility disability). Other mobility items found are getting around in the community, wheelchair use.

Measuring functional disability varies in approach depending upon the how BADLs and IADLs are combined (Spector and Fleishman, 1998). One very common approach is to use them as separate constructs. A second approach is to only use the IADL measure for those without BADL disability thus creating one construct with a summary score from the two measures. A third approach, taken by Spector and Fleishman (1998), was to develop a functional disability score from both measures using factor analysis and item response theory (IRT). Their findings demonstrated that the two measures are not hierarchically related and a simple sum could be used to derive a measure of functional disability. Using Guttman scaling and IRT, LaPlante

(2010) found that an IADL/ADL scale measuring "need for help" is hierarchical, unidimensional, and unbiased for age as compared to the classic ADL measure.

There is also no agreement as to which items to include and in which measures if BADLs, IADLs, and mobility are used separately. Often a respondent is asked for each component item if they have had difficulty performing the task in question and if so, how much difficulty. The items can then be used as a scale. Items have been asked dichotomously. Mobility items also lend themselves well to being used as performance measures (Guralnik, 2011).

D. Public Health's Role in Disability

Public health grew out of an effort to reduce mortality and later to reduce morbidity, but has responded slowly to the health needs of the disabled population in part because disability outcomes are not as clearly defined as mortality and morbidity (Lollar and Crews, 2003). Furthermore, public health perspectives regarding disability have viewed disability as a "burden of disease" and a disparity in access to the environment Krahn, Putnam, Drum and Powers, 2006). Research and interventions are population based with measures focusing on morbidity, mortality, and quality of life. Intervention focuses on primary prevention and prevention of secondary conditions. The contemporary perspective (Krahn and Campbell, 2011) is that persons with disability are a minority group at increased risk for poor health with the primary outcomes being health status and health related quality of life (HRQOL) that are influenced by disease that results in disability. Disability is a negative outcome and represents a failure to prevent an undesirable state (Crews and Lollar, 2006). The emerging perspective (Krahn and Campbell, 2011) is where disability is viewed as one multiple determinants of health. Persons with disabilities are part of the general population and disability is just one of multiple risk factors for poor health.

Pope and Tarlov (1991) pointed to a first revolution in public health occurring with sanitation, basic nutritional needs, and immunization which resulted in 1) longer life expectancy, and 2) acute disease being joined with chronic disease as a focus of public health attention. They emphasize the challenge of creating a second revolution that centers on lifestyle and behavior as primary components in health promotion and disease prevention. They stress that traditional public health interventions have not had the same impact on chronic disease and its related disabling conditions.

Just over ten years after Pope and Tarlov (1991) conclude that public health has fallen short of impacting chronic disease, Albert, Im and Raveis (2002) discuss, in their American Journal of Public Health (AJPH) editorial, "Public Health and the Second 50 Years of Life," how little the discipline has promoted public health in people 65 years and older. To illustrate this they randomly sampled nine of twelve issues of AJPH published in 2001 and counted original research articles that included people over 50 years of age. Twenty-two percent of the articles addressed persons 50 years or older and many of those studies did not have study populations over 65 years of age.

In the same editorial, Albert, Im and Raveis discuss three pathways to disability in aging and identify public health strategies to modifying those pathways. In their model, a distinction is made between the physiological changes of aging that are not disease-based and lead to frailty and subsequent disability, comorbid conditions added to senescent changes that lead to disability, and the social and psychological environmental factors that result in disability. They reference a study by Freid, Tangen, Walston, et al (2001) where 18% of the study population of 363 older adults had a disability that was likely the result of complex environmental, psychological and social factors. Albert, Im and Raveis recommend that the public health research community

direct more attention to the second 50 years of life and conclude that the AJPH is a good place to start. Although not explicitly stated, there is an implication that people aging *with a* disability might be included in the category of requiring more direct attention in the next 50 years.

Responding to this editorial, Crews and Smith (2003) specifically highlight the concept of aging *with a* disability. They suggest that persons aging with a disability need to be included in the "second 50 years" and recommend that aging and disability need to be modeled together. They conclude that consideration should be given to specific disabilities when designing public health interventions directed at aspects of health such as secondary conditions.

Illustrating how the disability and public health communities can build a future together, Rimmer (2011) explains how disability can be a component of each Section of the American Public Health Association. Because disability cuts across every area of public health, having Disability Section members who are knowledgeable in a second content area belong to both Sections would facilitate communication between all the stakeholders. Rimmer uses the Gerontological Health Section as an example and cites modern medicines advances leading to millions of adults who are aging with disabilities and facing secondary conditions as just one of risk factors that challenges successful aging. Taking secondary conditions, he uses prevention and health management strategies to tie public health, aging with a disability and aging into disability together and thus the communities of each.

E. Disability Groups: Polio and Rheumatoid Arthritis

The two disability groups used in this analysis represent two very different disease courses as well as distinct ages at onset. Poliomyelitis is caused by a viral infection and has an acute onset with paralysis. Rheumatoid arthritis is a progressive systemic inflammatory disease that affects the joints of the body and can have a fluctuating disease process.

1. Poliomyelitis and Post-Polio Syndrome

Poliomyelitis has been eradicated in much of the world. According to the Polio Global Eradication Initiative (http://www.polioeradication.org/), the last case of the wildpolio virus type 3 (WPV3) strain of polio was reported in Asia occurred on the 18th of April 2012 in Pakistan. Nigeria, until very recently, was the only country worldwide that has reported a new case of WPV3 and that was on the 10th of November 2012. The wildpolio virus type 2 (WPV2) strain was eradicated in 1999. If there are no new cases of WPV3, it will be the second strain eradicated. Wildpolio virus type 1 (WPV1) remains with these cases located in third world countries. This strain had not been detected in the Syrian Arab Republic since 1999, however, due to civil conflict in the country, vaccination rates have fallen dramatically form 91% in 2010 to 68% in 2012 resulting in ten confirmed cases on October 17 of this year. These cases are of mostly children under two years old and there are more cases yet to be confirmed (World Health Organization, 2013).

The development of the polio vaccine has lead to near eradication worldwide and is a remarkable achievement. However, there are an estimated 2.1 million Syrian refugees in five neighboring countries: Lebanon, Jordan, Turkey, Iraq, and to a lesser extent, Egypt (Hummer, 2013). The risk is considered to be high for the infection to spread to these neighboring countries and beyond (World Health Organization, 2013). With the refugee situation and an increasingly global mobile society, the success of near eradication is potentially jeopardized.

The last case of polio was in 1979 (Centers for Disease Control, 2013). Halstead (1987) estimated that there are 250,000 persons still alive in the United States who contracted paralytic polio before the vaccines were introduced in 1955. If one includes both paralytic and non-paralytic cases, there may be as many as 1.6 million survivors (National Center for Health

Statistics, 1989). The National Institute of Neurological Disorders and Stroke (2012) has slightly different figure and acknowledges that the incidence and prevalence of those with post-polio syndrome is not known as no survey has been conducted since the U.S. National Health Interview Survey in 1987. They estimate that there are 443,000 paralytic polio survivors out of one million with about 25 – 40% having developed post-polio syndrome.

A phenomenon began emerging among polio survivors that was first identified in 1875 by Raymond and Charcot (Dalakas, 1995) as "overuse." This theory is still discussed today as the primary cause of post-polio syndrome (PPS). Halstead (1992) established the term "post-polio syndrome" and defined it as those persons who were symptomatic in regard to both new health problems and functional limitations. PPS is characterized by new muscle weakness, muscle wasting, fatigue, and muscle or joint pain that result from an earlier episode of poliomyelitis (Halstead, 1988; Mulder, 1995; Dinsmore, 1998). A diagnosis of PPS requires that an individual must report two or more of these symptoms and have a least one new activity of daily living (ADL) limitation. These new symptoms typically appear about 25 to 40 years after infection (Grimby and Jonsson, 1994), however, the PPS diagnosis only requires a period of at least 15 years of neurologic and functional stability (Halstead and Rossi, 1987). Additionally, no other medical diagnosis should explain the new health problems in order for the diagnosis of PPS to be used (Halstead and Rossi, 1987). The diagnosis of PPS is one of exclusion where all other possible causes must be ruled out, thus making a diagnosis more challenging with possible coexisting conditions attributable to aging (Farbu, 2009). Late-onset sequelae of poliomyelitis (LOSP) is a term used to refer to new symptoms in a person who has polio, but does not meet the criteria for post-polio syndrome. These symptoms may be secondary conditions related to prior polio.

Wiechers, and Rossi (1985), and Halstead and Rossi (1988) found significant relationships between historical period and age at acute onset, and between age of onset and severity of initial impairment. Fewer limbs were affected by weakness or paralysis if the polio was contracted before the age of 10 compared to those whose onset of polio was during adolescence or young adulthood. Campbell (1994) found significant effects between age and historical period of acute onset in predicting both the severity of initial impairment and the presence of PPS. Their data are consistent with prior studies (Dauer, 1955; Weinstein, Aycock, and Feemster, 1951; and Weinstein, 1957; Halstead, Wiechers and Rossi, 1985; Halstead and Rossi, 1988) and provides evidence that stage in the life cycle when polio was contracted and historical context impacts how impaired an individual was by the virus. Their results show that as both the age at acute onset and the decade in which polio occurred increases, so does the percentage of the sample with 3 and 4 limbs affected (as opposed to 1 or 2 limbs). Significant increases occurred for those who had polio at 10 years or older and who contracted it after 1940.

There are three major symptoms associated with post-polio syndrome: new muscle weakness, fatigue and pain. The hallmark symptom of post-polio syndrome is new muscle weakness (Gawne and Halstead, 1995). The pattern of new weakness, sometimes accompanied by atrophy, presents as slowly progressive, asymmetrical and scattered, occurring in either previously affected or muscles that were not affected during the acute episode (Jubelt and Agre, 2000; Silver and Aiello, 2002; and Farbu, 2009), as well as those affected subclinically (Farbu, 2009). Additionally, increased activity results in exacerbation of the weakness by the end of the day (Silver and Aiello, 2002). Related to new weakness is the overuse of these abnormally fatigued muscles that require extensive rest to recover (Jubelt and Agre, 2000). Research with regard to functional muscle strength/new weakness is limited. Nollet, Belen, Prins et al (1999)

looked at persons with and without PPS in a study of polio survivors with late-onset sequelae of poliomyelitis (LOSP) and found no difference between the two groups in manually tested strength, however, the PPS group required more time for performance testing and their perceived exertion was higher. Stolwijk-Swuste, Beelen, Lankorst, et al (2005), in a systematic review of the literature to identify prognostic factors associated with change in functional status and muscle strength, identified 19 studies related to these factors and found either insufficient quality or inconsistent results.

Fatigue is the most frequent and debilitating symptom reported by people with PPS (Packer, Sauriol, and Brouwer, 1994; Nollet, Beelen, Prins et al, 1999; Jublet and Agre, 2000; Schanke and Stanghelle, 2001; Nollet, Beelen, Twisk et al, 2003; and Trojan and Cashman, 2005). It can lead to limitations in activities of daily living (ADL), social participation, and work duties (Packer, Sauriol, and Brouwer, 1994). Associations between fatigue and physical and psychological variables have been found by several investigators (Ostlund, Wahlin, Sunnerhagen et al, 2008; Trojan, Arnold, Shapiro et al, 2009; and Tersteeg, Koopman, Stolwijk-Swuste et al, 2011). In their study, Trojan, Arnold, Shapiro et al (2009) conclude that PPS fatigue is complex and multidimensional, having three parts: general, physical and mental. Each of these parts is determined by different variables, some fixed (maximum inspiratory pressure, fibromyalgia, muscle strength, maximum expiratory pressure, age, time since acute polio) and others that are modifiable (stress, depression, physical activity, pain).

Pain is a common primary symptom of PPS. The prevalence of muscle pain has been estimated to be 38% to 86% of patients and joint pain between 42% to 80% of patients. Jubelt and Agre (2000) aggregated data from three states. Muscle and joint pain were reported separately and were found to be similar. This held true for three of the four sites where the

percentages of those with muscle/joint pain were 94/94%, 74/72% and 73/73%. The percentages at the fourth site were 68/61%.

Researchers have shown an association between pain and fatigue (Vasiliadis, Collet, Shapiro et al, 2002; Trojan and Cashman, 2005; Stoelb, Carter, Abresch et al, 2008; Trojan, Arnold, Shapiro et al, 2009; Jensen, Alschuler, Smith et al, 2011; and Tersteeg, Koopman, Stolwijk-Swuste et al, 2011) and joint pain and muscle weakness (Vasiliadis, Collet, Shapiro et al, 2002). Pain can involve either muscles and/or joints (Jubelt and Agre, 2000; Trojan and Cashman, 2005; and Farbu, 2009). Stoelb, Carter, Aresch et al (2008) investigated pain with respect to frequency, intensity and impact. Ninety-one percent of their sample reported pain. Shoulders, lower back, legs and hips were where the most frequently reported sites. Participants reported an average of 10 areas of pain, the most intense being found in the knees, legs, wrists, lower back and head. Sleep and activities involving a high level of musculoskeletal effort were affected most by pain. Finally, respondents' pain problems were more severe compared with the general population.

There is no single basis for muscle or joint pain (Halstead, 1987). It can be the result of overuse (Halstead, 1987 and Farbu, 2009), disuse (Halstead, 1987) or compensatory use of unaffected muscles (Farbu, 2009). Vasiliadis, Collet, Shapiro et al, (2002) suggest that greater initial motor unit involvement and lower-extremity weakness may be important factors for determining joint pain. They investigated muscle and joint pain independently and found significant predictive factors for muscle pain were being female gender, longer duration of general fatigue and a lower score on the general health scale of the SF-36. Joint pain factors were female gender, longer duration of stability after the acute onset, younger age at interview, greater weakness at acute polio, weaker lower-extremity muscle strength, and a lower general

score on the SF-36. Willen and Grimby (1998) reported physical activity in daily life as a correlate of pain. Contradicting Willen and Grimby's findings, Östlund, Wahlin, Sunnerhagen, and Borg (2008) found that low levels of activity and psychological functioning were correlates of pain.

With respect to how those with PPS symptoms are aging, Stolwijk-Swiiste, Tersteeg, Beelen et al (2010), in a prospective study, examined the impact of age and comorbidity on late-onset sequelae of poliomyelitis in a cohort of patients consisting of varying ages and levels of comorbidity. They found that disability increased little despite a sizable reduction in muscle strength. Interestingly, comorbidity and the extent of paresis negatively influence functional independence only, not perceived physical functioning. They hypothesize that persons with LOSP may be able to maintain their physical functioning at the cost of their progressively weakening muscles, thus causing the symptoms of pain, fatigue and muscle weakness associated with post-polio syndrome.

2. Rheumatoid Arthritis

Rheumatoid arthritis (RA) is a chronic syndrome that is a progressive, usually symmetrical, inflammatory disease resulting in peripheral joint and connective tissue damage (Berkow, 1991). It can also affect multiple organ systems such as cardiovascular, renal and respiratory systems, and has an autoimmune component (Hootman, Helmick and Brady, 2012). Symptoms include joint pain and swelling, stiffness, fatigue, and deformity, and can lead to severe disability. Treatment includes medications, rest and exercise, and surgical procedures such as joint replacements and tendon transfers to correct joint damage. RA affects individuals differently. Symptoms vary considerably with three major disease progressions (CDC, 2012; Pincus and Callahan, 1993): monocyclic (one major episode that lasts 2 – 5 years and does not

reoccur); polycyclic (fluctuating disease levels); and progressive RA (increases in severity and is unrelenting). Overall, the course of RA is highly unpredictable with exacerbations and remissions varying in length (Strating, Van Schuur and Suurmeijer, 2007).

Gender and age are the epidemiological characteristics of RA (Mongan, 1990). Although RA can occur at any age, including in children, onset is most frequently between the ages of 20 and 40 with women being three times more likely to develop it as compared to men (CDC, 2012). Data from the Rochester Epidemiology Project (Myasoedova, Crowson, Kremers et al (2010) placed the incidence of diagnosed cases of RA at 41 per 100,000 each year from 1995-2007 with incidence rising with age (8.7 per 100,000 in the 18-34 age group versus 54 per 100,000 in the 85 and older category). Incidence peaked in the 65-74 age group.

Prevalence is estimated to be 1.5 million persons 18 and older (Helmick, Felson, Lawrence, 2008). The Rochester Epidemiology Project (Myasoedova, Crowson, Kremers et al, 2010) calculated the overall age-adjusted prevalence for women in 1995 to be 7.7 per 1000 versus 4.4 per 1000 for men. In 2005, overall prevalence had risen for women to 9.8 per 1000, while it decreased slightly for men (4.1 per 1000 for men).

Although the incidence of RA increases with age, the sex-ratio decreases in age. The ≥ 60 group with RA has a different sex-ratio. The female-male ratio decreases with greater age (Kvien, Uhlig, Odegard, Heiberg, 2006). Deal, Meenan, Goldenberg, Anderson et al (1985) compared clinical features of elderly-onset rheumatoid arthritis with younger-onset disease and found that age at onset was an important determinant of the disease course, adjusting for joint scores, disease duration, abrupt onset and polymyalgia rheumatica (often misdiagnosed as RA in those older than 60).

The etiology of RA is not known and it is believed that in many cases there is an interaction between genetic factors and environmental exposures (CDC, 2012). Risk factors for RA fall into several categories: socio-demographic, genetic, modifiable, and reproductive and breastfeeding history (CDC, 2012). As previously indicated, women are three times more likely than men to develop RA, and onset is highest for men and women in their sixties. Genetically, human leukocyte antigen (HLA) class II genotypes are associated with increased risk of RA (Scott, Wolfe and Huizinga, 2010). Conditions that are considered risk factors are: smoking, diet, reproductive hormonal exposures, and microbial exposures (CDC, 2012). Research investigating the relationship between RA and smoking has demonstrated a strong, consistent link between the two, especially when have a marker of autoimmune activity (CDC, 2012).

With respect to reproductive and breastfeeding history, recent study results contradict earlier results and have found a lack of association between RA and oral contraceptives. There are mixed results for an association between RA and hormone replacement therapy and a slight to moderate increase in risk if a woman has never given birth (CDC, 2012). Breastfeeding has been found to be protective (Piker, Nilsson, Bergstrom et al, 2012). Finally, there have been mixed results concerning menstrual history. A study by Pikwer, Bergstrom, Nilsson et al., (2012) found an increased risk for RA in women who had early menopause (≤45 years of age). The same authors (Pikwer, Nilsson, Bergstrom et al, 2012) subsequently investigated severity of RA in association with menopause and found a milder form of RA in women who had early menopause (≤45 years of age) and whose disease onset was after the age of 45.

In an editorial, Sokka (2009) considers gender differences in persons with RA. She discusses the results (Sokka, Kautiainen et al, 2007) of a large multinational dataset that utilized standardized quantitative instruments. This study found that women had poorer scores than men

in variables such as, but not limited to, number of tender joints, functional status, pain and fatigue. Effect sizes between genders were small to medium despite statistical significance. With respect to swollen joints, those who had none or one, women had higher mean values than men in all disease activity measures and experienced remission less often. Women and men had similar disease severity however, leading the authors to suggest that the measures of disease activity resulted in the gender differences instead of the disease activity itself (Sokka, Hetland, Makinen et al, 2008; Sokka, Toloza, Cutolo, et al, 2009). A two year prospective study (Hallert, Thyberg, Hass, Skargren and Skogh, 2003) found women had more decline in functional ability, despite having similar scores as men on the disease variables. The men were, on average, older than the women.

The major symptoms associated with RA are pain, fatigue and joint stiffness, resulting in functional limitations. The most acute of which is pain (Kazis, Meenan and Anderson, 1983; McKenna and Wright, 1985; Heiberg and Kvien, 2002; Minnock, FitzGerald and Bresnihan, 2003). Pain is subjective. As Sokka (2005) observes, it is a personal experience that is underestimated by the traditional biomedical model. Additionally, response to pain varies vastly, adding complexity for health care professionals in the treatment of pain (Kazis, Meenan and Anderson, 1983). A qualitative study (Ahlstrand, Bjork, Thyberg et al., 2012) utilizing focus groups recommends that "pain in RA needs to be comprehensively analyzed and treated in the context of the patients' perspective and needs" (p. 1245). Pain is associated with health status (Kazis, Meenan and Anderson, 1983; James, Miller, Brown and Weaver, 2005), health behavior (Kazis, Meenan and Anderson, 1983), increased functional disability (Sokka, T., 2005; Strating, Van Schuur and Suurmeijer, 2007; Ahlstrand, Bjork, Thyberg, et al., 2012), psychological variables (James, Miller, Brown and Weaver, 2005; Sokka, T., 2005; Morris, Yelin, Wong and

Katz, 2008), longer disease duration (James, Miller, Brown and Weaver, 2005; Morris, Yelin, Wong and Katz, 2008), morning stiffness (Morris, Yelin, Wong and Katz, 2008); low self-efficacy (James, Miller, Brown and Weaver, 2005; Sokka, 2005; Morris, Yelin, Wong and Katz, 2008), and fatigue (Huyser, Parker, Thoreson, et al., 1998).

Although fatigue is one of the main complaints of rheumatoid arthritis, physicians do not show as much interest in treating it compared to other symptoms such as pain (Dupond, 2011). There is no clear definition because of its multidimensional nature. Piper (1989) developed an integrative model that took into account many factors, both biologic and psychosocial, when considering subjective fatigue. Generally, fatigue is considered to have two components: physical and psychological (Huyser, Parker, Thoreson, et al., 1998). Physical fatigue can involve muscle weakness, tiredness, excessive energy expenditure, inadequate energy production, and sleep disorders (Dupond, 2011). In his review paper, Dupond, (2011) classifies psychological fatigue as weariness associated with depression and stress. Huyser, Parker, Thoreson, et al (1998) characterize subjective fatigue as a sense of extreme tiredness or exhaustion which encompasses psychosocial (e.g., depression, anxiety), behavioral (e.g., activity levels), and environmental (e.g., social supports) factors. In their study, fatigue was strongly associated with pain, depression, and other psychosocial variables. In an effort to determine whether conventional RA drug therapies reduce fatigue, Pollard, Choy, Gonzalez, et al (2006) investigated the relationship of fatigue to pain and other clinical features, and whether two types of drug therapies improved fatigue. They concluded that fatigue was linked to pain and depression, disease activity was secondary, and the success of drug therapies was the result of improvement in pain. Droegemuller, Brauer and Van Buskirk (2008), looked at the influence that temperament (positive affectivity, negative affectivity, constraint) has on fatigue and symptom

management strategies. They found that temperament was a significant factor in managing fatigue and additionally, older individuals were more successful in symptom management strategies.

While morning/joint stiffness is a major symptom of RA, studies taking into account symptoms have reported morning stiffness to be either not significant or less of a concern than pain and fatigue (McKenna and Wright, 1985; Hallet, Thyberg, Hass et al., 2003). There is little discussion about how morning stiffness fits into the scheme of the disease with regard to those quantitative studies that measure morning/joint stiffness. In a qualitative study, Lutze and Archenholtz (2007) were able to contextualize the impact morning stiffness has on daily routines using focus groups. Even though morning stiffness may not be statistically significant (Hallet, Thyberg, Hass et al., 2003) or ranked lower in priority (McKenna and Wright, 1985) by subjects in quantitative studies, the authors show how impactful it can be in the daily lives of persons with RA. The American College of Rheumatology's (ACR) 1987 criteria have been revised as they have poor sensitivity and specificity in diagnosing early inflammatory disease that goes on to become rheumatoid arthritis (Banal, Dougados, Combescure and Gossec, 2009). The revisions were made in conjunction with the European League Against Rheumatism (EULAR). A criterion in 1987 was "morning stiffness (at least 1 hour)." The new 2010 ACR/EULAR criteria (Aletaha, Neogi, Silman, Funovits et al, 2010) do not use morning stiffness as a criterion; instead the criterion is "duration of symptoms" and refers to pain, swelling or tenderness of joints. Morning stiffness has been removed.

III. CONCEPTUAL FRAMEWORK AND HYPOTHESES

A. Life Course, Disability Trajectory and Disablement

A life course perspective helps to frame and anchor disability and life events. It illustrates the timing of age-related transitions and the timing and changes due to disability. Conceptually, studying aging with disability requires integrating several theoretical approaches with measures of impairment and function from the fields of adult development, social gerontology, disability and rehabilitation (Campbell, 1994). Campbell (1994) adapted Scheer and Luborky's (1991) framework of the "disability trajectory" and incorporated the biopsychosocial model of rehabilitation (Kemp, Brummel-Smith and Ramsdell, 1990) with the life course perspective. The conceptual framework for this dissertation applies this integrative approach to aging with disability utilizing the foundation of a life course perspective. Aging is viewed as a lifetime process where events that occur during one's "younger" years can dramatically effect how one ages.

The polio experience of the disability trajectory is used in Figure 1 to illustrate the conceptual life course framework of Campbell (1994). This conceptualization can be adapted for any disability where the "disability trajectory," or timeline, and historical period will vary. It highlights the complexities of aging with a disability by depicting the multiple variables that must be considered to clearly understand each disability's unique characteristics, each individual's unique situation in life, and how the two interact.

There are two components of the horizontal axis. The bottom represents the disability trajectory (Scheer and Luborsky, 1991), or timeline, from birth to death. This is the temporal structure of disability-related events and takes into account onset of primary and secondary disability (Campbell, 1994). The upper component of this axis represents chronological age

within the life span and is the most closely associated with physiological aspects of aging (Scheer and Luborsky, 1991). The vertical axis represents the historical period in which an individual is born, acquires the disability, and ages (Scheer and Luborsky, 1991). This axis is influenced by macro-level changes in societal attitudes and policies as well as advances in medicine and rehabilitation, all of which shape the context individual and social aging (Campbell, 1994). The diagonal axis is comprised of social aging and put into context within the life course stages or transitions from childhood to old age (Scheer and Luborsky, 1991). Social aging corresponds to the developmental stages of an individual that are culturally defined and normative.

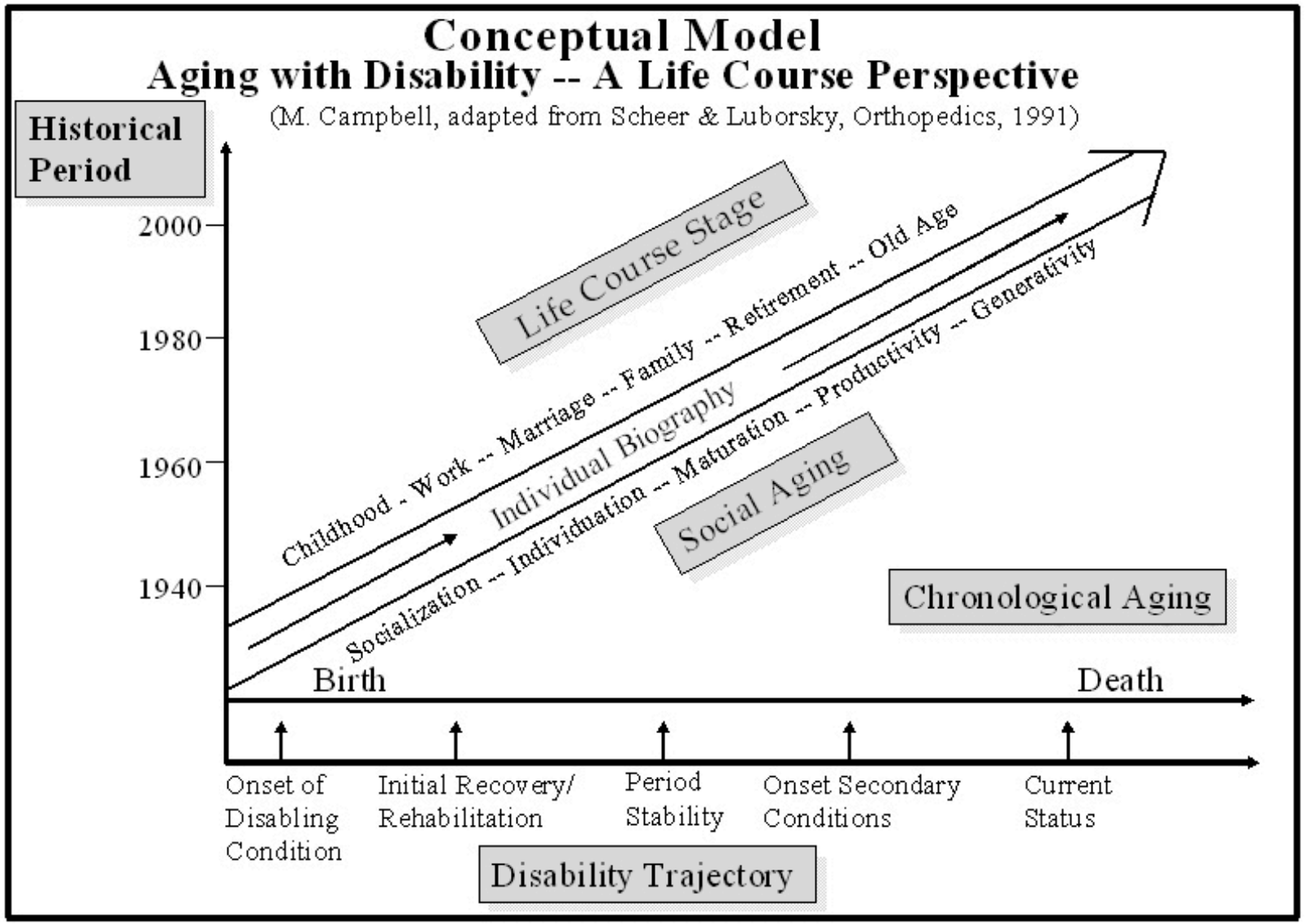

Figure 1. The Aging with Disability Study Conceptual Model

Underlying this conceptual framework is the Institute of Medicine's (IOM) model of the disabling process (Pope and Tarlov, 1991) which builds on Nagi's (1965) framework of pathology (stage 1), impairment (stage 2), functional limitation (stage 3) and disability (stage 4). Figure 2 shows the domains and items used in this analysis that are measured in each of the stages of the IOM model. Chronic conditions represent the secondary pathology in stage one. Severity of pain, fatigue, and muscle weakness for polio or joint stiffness for rheumatoid arthritis represent the impairment stage. The third stage, functional limitations, consists of items related to mobility. The final stage, disability, is represented by difficulties in instrumental activities of living (IADLs), such as getting around in the community, shopping, meal preparation, etc. As discussed earlier, the IOM model does not specify a unilateral stepwise direction from pathology to disability. Although each stage in the disabling process usually occurs this way, an individual may skip over one of the stages (Pope and Tarlov, 1991). Each stage can be influenced by risk factors and quality of life. They also point out that the effects of any stage can be moderated by interventions such as assistive devices.

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) model provides a comprehensive model of disability as discussed earlier. However, the conceptual aspects of the domains of activities and participation are problematic. In discussing the one-model fits all approach, Guralnik and Ferrucci (2009) point to sudden catastrophic disability in a younger individual where a disablement model might not be useful. Yet when disability is progressive, Nagi's model is useful for identifying the stages over time and allowing for interventions along the pathway. Polio and rheumatoid arthritis are progressive diseases that are extremely suitable for the IOM model.

The Disablement Process

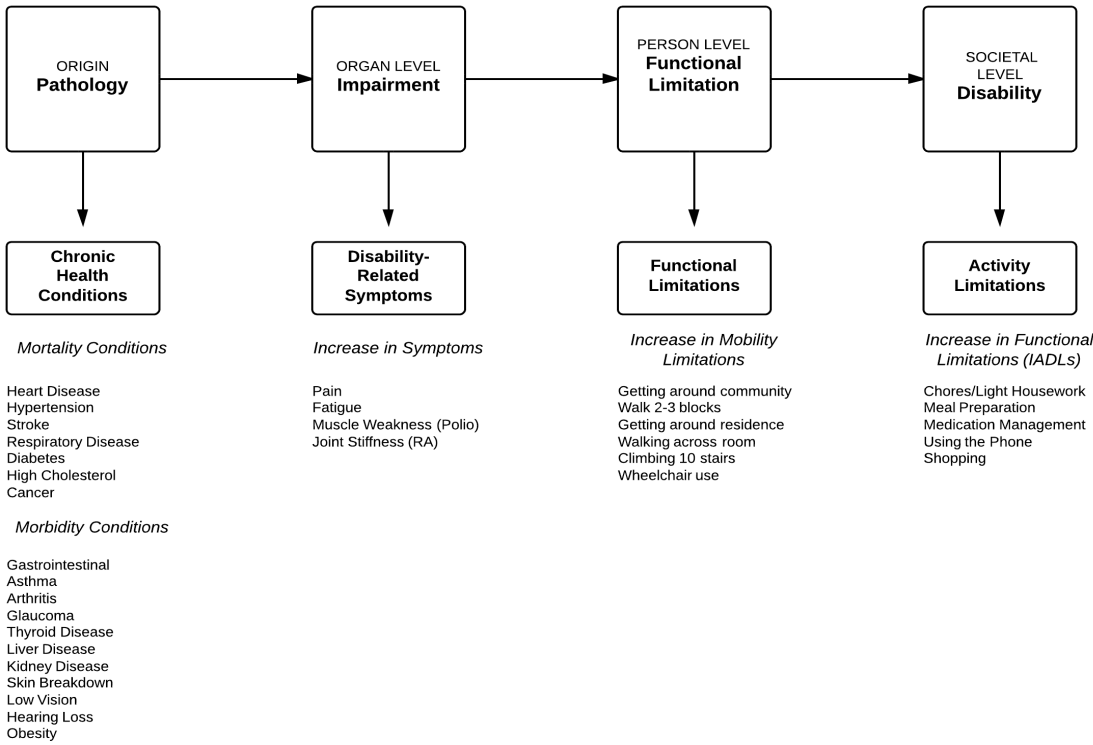

Figure 2. Institute of Medicine (IOM) Model of the Disablement Process and Corresponding Domains Being Utilized

B. Models

Aging with disability models correspond to both conceptual frameworks of life course perspective (processes of time that influence aging) and disablement (processes of change that contribute to secondary conditions and disability). The disability trajectory variables are the temporal anchors. They place the disability onset on the aging timeline. The increases in symptoms variables are disability-related secondary conditions and in effect, begin the active disablement process. Increase in mobility limitations, chronic secondary health conditions (due to aging and/or the primary disability), and increase in functional limitations (IADL) are all different components of secondary conditions. As discussed earlier, these pathways do not necessarily follow a prescribed course.

The concepts of the disability trajectory paired with chronological aging, historical period and life course framework are illustrated in Figure 1. Figure 2 places the components of the models into the framework of the disablement process. Figures 3 and 4 operationalize the relationships among the components for post-polio syndrome and rheumatoid arthritis respectively. Although the two models are very similar in structure, they differ in one very crucial respect. Polio and rheumatoid arthritis have profoundly different disability trajectories that are reflected in the different variables in Figures 3 and 4. The trajectory variables anchor the disability at different life courses and are hypothesized to result in differences between polio and RA with respect to their disease courses. Polio has an average age of childhood as an onset while RA has an onset of young middle age. Both onset variables and status at physical best for polio and status at reference period are related to disease, but where RA is an intermittent autoimmune disease, polio is an acute onset disease that leaves one with paralysis.

Number of disability bed days (in six months) is the outcome for the fully specified models for polio and RA. Disability bed days is generally used in health care utilization research. Its utility is that it captures disability burden for both employed and unemployed individuals as opposed to work loss days that only capture disability burden for the employed (Egede, 2004). Disability bed days is a strong outcome measure in these data. An earlier analysis (Campbell, Sheets, Rhaney and Moulton, 1999), analyzed data on a combined AwD sample of polio, RA and stroke. It focused on four quality of life indicators: depressive symptoms, self-assessed health, number of physician visits in past year, and unmet need for services. The analysis found that number of disability bed days was associated with lower quality of life of life across all four indicators ($p<.001$ each).

Work status is included in the final model as a control for disability bed days. Table 5 in Methods contains the demographic differences between the polio and rheumatoid arthritis samples. Thirty-one percent of individuals with rheumatoid arthritis had never worked since disease onset as opposed to only nine percent for individuals with polio.

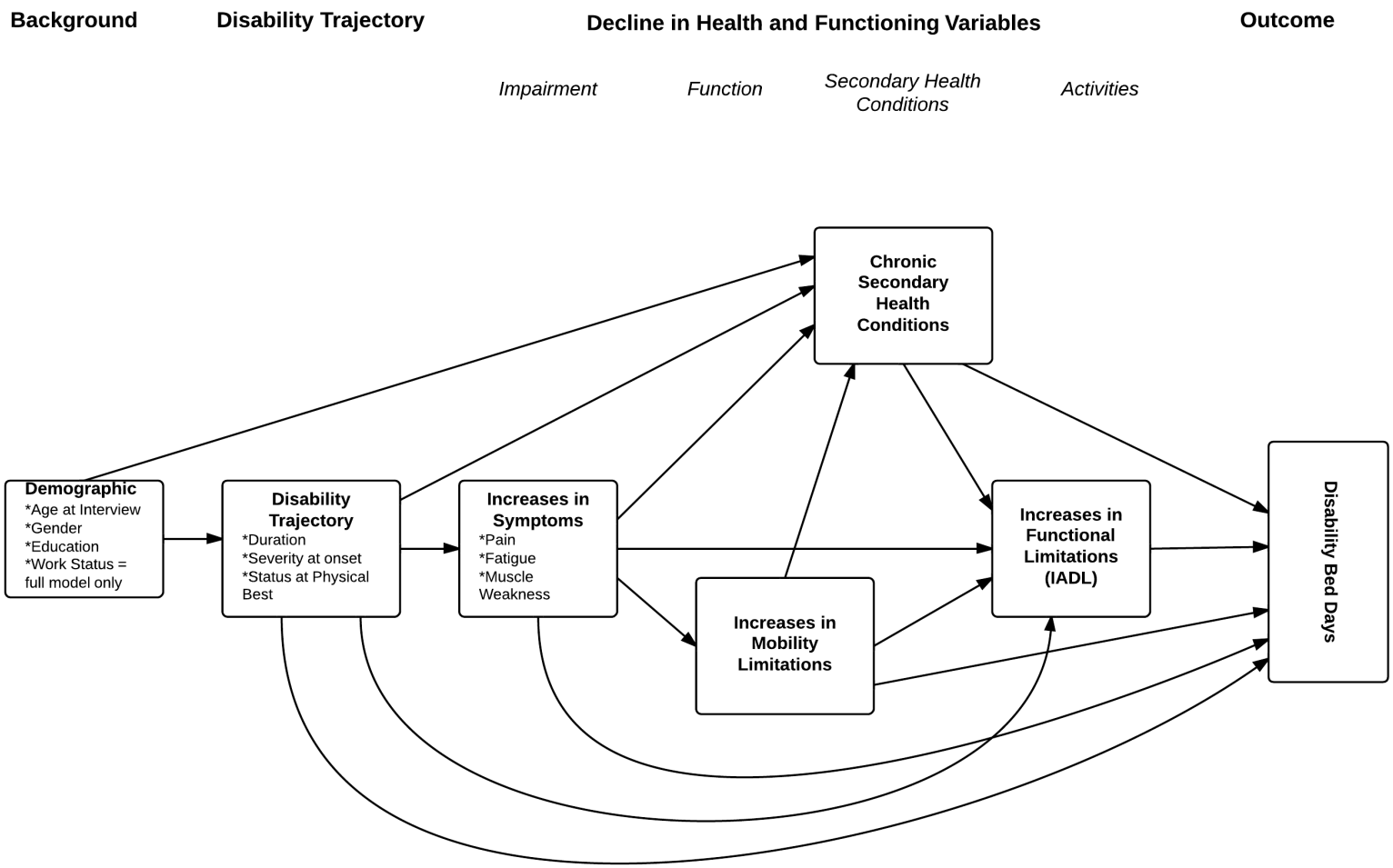

Figure 3. Conceptual Model for Predicting Disability Bed Days: Polio

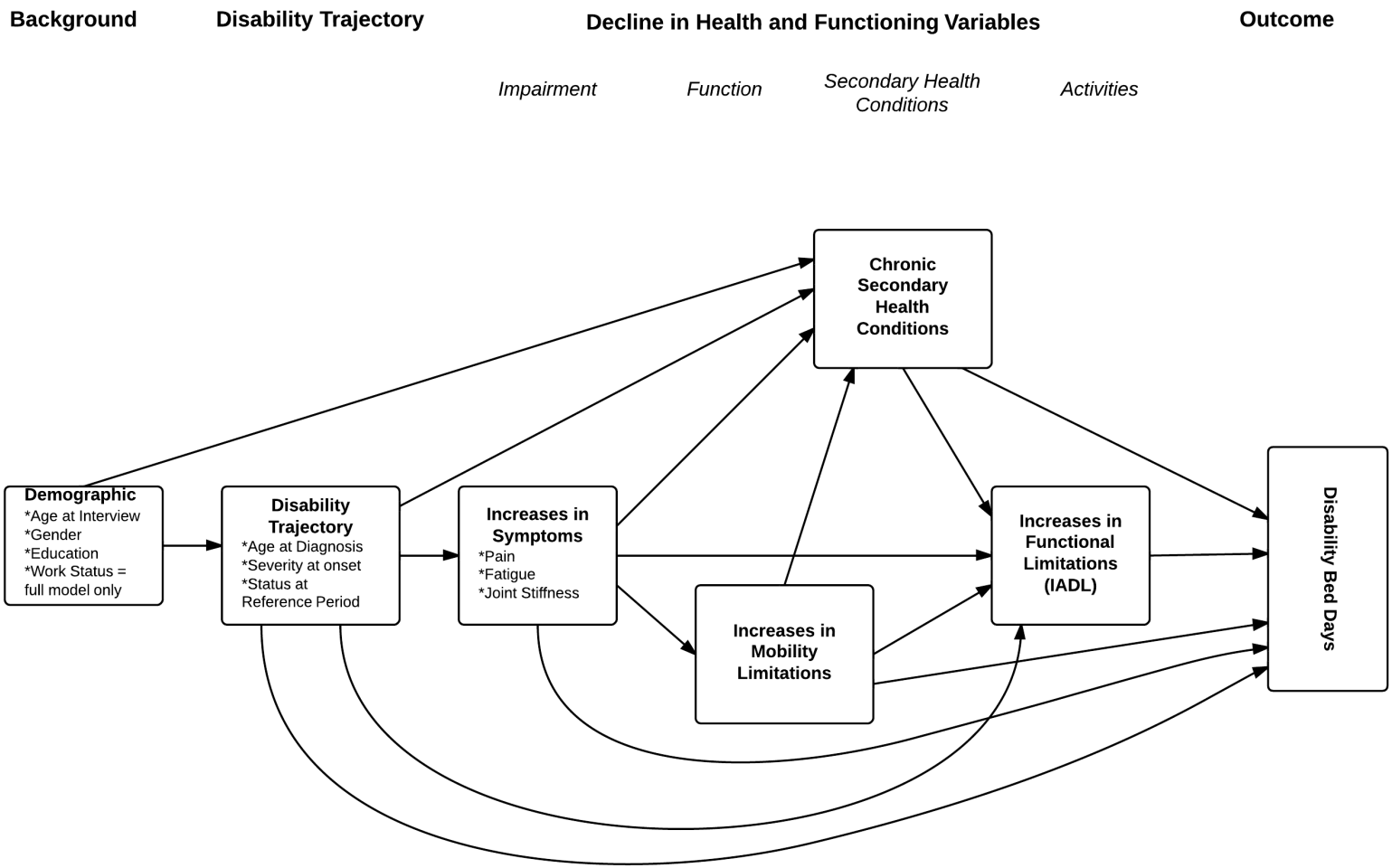

Figure 4. Conceptual Model for Predicting Disability Bed Days: Rheumatoid Arthritis

C. Conceptual Models and Hypotheses

Utilizing the integrated conceptual life course and disablement framework conceptualized in Figures 3 and 4, three hypotheses for each disability group were deduced which address interrelationships among the components of secondary conditions, explore the disability characteristics, and examine the effects of secondary conditions on disability bed days. An overall hypothesis compares secondary conditions between disability groups. The same general empirical pattern is deduced for the first three hypothesis, but disease-specific mechanisms are discussed that may give rise to secondary but important differences between the two. The overall hypothesized pathway examines predictors and outcome variable between the two disability groups.

1. Polio Hypotheses

a. Interrelationships Among Components

For those aging with polio, increases in mobility limitations will be more strongly related to increases in functional limitations than to the number of chronic secondary health conditions, controlling for demographic and disability characteristics.

Mobility limitations in polio are associated with severity of the initial onset of polio and the duration of the disease. Severity of initial onset increases risk for post-polio syndrome. Because of the neurodegenerative nature of post-polio syndrome, its characteristic new muscle weakness contributes to mobility and functional limitations.

b. Unique Disability Characteristics

For those aging with polio, disability trajectory indicators (severity of initial onset, duration of disability and status at physical best) will be more strongly related to increases in functional limitations than to the number of chronic secondary health conditions controlling for demographic characteristics for individuals aging with polio.

For individuals with polio, a more severe initial impairment at onset and longer disability duration contributes to mobility limitations that lead to faster deterioration in mid-life and in functional abilities. The initial impact of polio varied significantly for individuals and that has an impact on their longer-term functional outcomes.

c. Disability Bed Days

For individuals with aging with polio, increases in symptoms (pain, fatigue, muscle weakness), increases in mobility limitations and increases in functional limitations will be stronger predictors of the number of disability bed days in the last six months than will the number of chronic secondary health conditions, controlling for demographic and disability characteristics.

Because of the neurodegenerative nature of post-polio syndrome, its characteristic new muscle weakness contributes to mobility and functional limitations. It is also characterized by paralysis and musculoskeletal involvement, hence, increases in mobility and functional limitations.

2. Rheumatoid Arthritis Hypotheses

a. Interrelationships Among Components

For those aging with rheumatoid arthritis, increases in symptoms (fatigue, pain and joint stiffness) will be more strongly related to increases in functional limitations than to the number of chronic secondary health conditions, controlling for demographic and disability characteristics.

RA involves an autoimmune disease process that typically has a fluctuating disease course and variability in severity. It typically affects upper body joints (e.g. hands), causes pain, fatigue and joint stiffness. Increases in symptoms indicate that a more unstable disease process is occurring and therefore functional decline is related to activities that involve more upper body use.

b. Unique Disability Characteristics

For those aging with rheumatoid arthritis, disability trajectory indicators (severity of initial onset, age at diagnosis and status at reference period) will be more strongly related to the number of chronic secondary health conditions than to increases in functional limitations controlling for demographic characteristics for individuals aging with rheumatoid arthritis.

Individuals with rheumatoid arthritis have a more a fluctuating disease course with variability in severity, which can depend upon severity of initial onset. Those who are older when they develop it can have a more severe form. The rheumatoid arthritis disease process progresses over time with deteriorating functioning, however, with treatments such as surgical

joint replacement, the disability trajectory can be changed with restoration of function. A compromised immune system from the disease and pharmaceutical treatments will increase the risk of acquiring chronic secondary health conditions.

c. Disability Bed Days

For individuals aging with rheumatoid arthritis, the number of chronic secondary health conditions will be a stronger predictor of the number of disability bed days in the last six months than will increases in symptoms (pain, fatigue, joint stiffness), increases in mobility limitations and increases in functional limitations, controlling for demographic and disability characteristics.

Rheumatoid arthritis can affect multiple organ systems such as cardiovascular, renal and respiratory systems, and has an autoimmune component. Individuals with rheumatoid arthritis tend to have more treatment options available to them, including drug therapies and joint and tendon surgeries, thus, increases in symptoms, increases in mobility limitations and changes in functional limitations would not be as strong of a predictor of disability bed days as chronic secondary health conditions. Drug therapies for rheumatoid arthritis are a double-edged sword. They can slow the disease progression, thus limiting declines in mobility and function, however they can have serious side effects that can contribute to chronic secondary health conditions.

3. Comparison of Disability Group Differences

Based on measures available for those aging with polio rheumatoid arthritis, relationships between predictors and outcomes (controlling for demographic variables) will not consistently be stronger for either disability group. This hypothesis applies to the common predictors of increases in chronic secondary health conditions (three

predictors), increases in functional limitations (four predictors), and the number of disability bed days in six months (five predictors).

IV. METHODS

A. Study Design For Secondary Data

Data for this secondary analysis are taken from the Aging with Disability (AwD) Study (Campbell and Sheets, 1996) conducted between 1996 and 1997 at the Rehabilitation Research and Training Center (RRTC) on Aging with Disability located at Rancho Los Amigos Medical Center in Downey, California. The RRTC is also an affiliate of the University of Southern California. The study was funded by the National Institute of Disability and Rehabilitation Research in the U.S. Department of Education. It involved in-depth structured in-home interviews consisting of objective and subjective self-reports of current status and prior condition. The survey was a regional cross-sectional, group comparison design with a cross-sequential sampling and data analytic framework.

The AwD Study compared age-matched persons aging with early and later-life onset of disability in the areas of physical, psychological, and social status. Data were collected from 555 persons aging with polio, rheumatoid arthritis (RA) and stroke. Research objectives were to determine if there were significant differences within and between disability groups with respect to health status; and to investigate how age, duration of disability, and other factors related to aging and disability influence these differences. For the purposes of this dissertation the stroke sample was not utilized. Stroke often results in residual neurological impairment thus there were differences in how some of the questions for this analysis had to be asked. A total of 404 cases (n=218 for polio and n=186 for rheumatoid arthritis) were used for this dissertation.

1. Instrumentation

Data for the AwD study were collected using a comprehensive survey entitled “The Changing Needs and Life Circumstances of People Aging with Physical Disability” (Campbell

and Sheets, 1996). It was developed over a two-year period with considerable input from a ten member Consumer-Oriented Research Advisory Committee (CORAC) composed of persons with disability who were experts in their respective impairments.

The same survey instrument was administered to both the polio and RA groups to allow for comparisons across samples with the exception of a section that was specifically designed to address each particular disability. The history of the disability component was adapted for each disability group to reflect the unique characteristics of the different disabilities. Items in this section were carefully constructed to be able to make meaningful comparisons on similar items between disabilities. Six major content areas were addressed: history of disability; demographic characteristics; physical health status and services; functional ability, technology and accessibility; social issues; and psychological well-being/lifestyle practices.

It was anticipated that the survey would be comprised primarily of existing measures rather than having to develop a new instrument. After systematically evaluating over one hundred scales and instruments from both the fields of gerontology and rehabilitation, Campbell and Sheets (1996) found that using existing measures was problematic due to the limited scope of cross-disability research. Studies of change in the health and function of persons aging with disability are rare. Ultimately, many of the questions in the AwD Survey were borrowed or modified from other studies. The final survey was a combination of objective and subjective self-reports regarding prior and current health status that included selected scales and items from:

1. Basic and Instrumental Activities of Daily Living (National Health Interview Survey, 1994);
2. Diagnoses/Chronic Health Conditions (National Health Interview Survey, 1994; Surveillance Instrument of Secondary Conditions, Seekins et al., 1990);

3. Functional Limitations (National Health Interview Survey, 1994);
4. Pain (Quantitative Pain Scale, SF-36 Medical Outcomes Study (Ware, 1992);
5. Fatigue (National Health Interview Survey, 1994; SF-36 Medical Outcomes Study - Ware, 1992);
6. Joint Stiffness (RADAR Scale, Mason et al., 1992); and
7. Severity of Impairment (National Health Interview Survey, 1994; Later Life Effects of Earlier Life-Disability Study, Campbell, 1994; Late Effects of Polio Study, Maynard et al., 1991)

One unique aspect to the AwD survey instrument is that it incorporates a disability perspective within a life course framework, thus taking into account temporal characteristics of the disability trajectory.

Cross-disability research faces many challenges in constructing variables that can compare over time changes in health status across disability (Campbell, Sheets, and Strong, 1999). To address some of these concerns, temporal indicators were established for each disability to reflect the varying nature of the disease course (Campbell & Sheets, 1996). These temporal indicators illustrate the disability trajectory. With respect to the polio population, five reference points were established: onset of disabling condition; initial recovery/rehabilitation period; period of stability ("physical best"); onset of decline (beginning of changes in health and function); and current status as of time of interview. For those who reported no "physical best," "five years ago" was used as the reference point. The conditions that occurred between the onset of decline and time of interview were considered secondary conditions. The other temporal indicators, such as age at onset of the disease, the length of time between onset of disability and

time of interview (duration of disability), and length of time between onset of decline and time of interview (duration of decline) were conceptualized as risk factors for secondary conditions.

Rheumatoid Arthritis required a different set of temporal indicators due to the fluctuating nature of the disease. Three reference points were established: age at diagnosis, an intermediate reference period, and time of interview. With respect to the intermediate reference period, subjects were asked if they were in either a "good period," remission, or a "bad period." A good period was defined as a stable period with mild disease activity. Remission was defined as no disease activity, that is, an absence of arthritis pain and swelling. A time of active exacerbated disease defined a bad period. The reference period was considered the most recent change in disease activity. Thus, if a subject were in a good period at time of interview, their reference period would be their most recent bad period. If the subject were in a bad period, then their reference period would be their most recent remission or good period. "Five years ago" was used if subjects did not feel that these reference periods were applicable. (See Table 1.) Secondary conditions for the RA sample were defined as declines in health and function occurring between the reference period and time of interview. Following the polio sample, the other temporal indicators were conceptualized as risk factors for secondary conditions, e.g., age at diagnosis and duration of disability.

Table 1. Establishment of Reference Period for Rheumatoid Arthritis Sample

Rheumatoid Arthritis	
Intermediate Reference Period	**Time of Interview**
Bad Period	Good Period
Good Period	Bad Period
Good or Bad Period	Remission
5 years ago	Good Period, Remission, Bad Period

2. Study Sample

The sample for the present secondary analysis consists of working-age and older adults living with the long-term effects of two disabling conditions: polio and rheumatoid arthritis (RA). These two groups represent a natural examination in the life course differences between disabilities in which onset primarily occurs in childhood (i.e., polio; n=218) versus young to middle adulthood (i.e., rheumatoid arthritis; n=186). Subjects were randomly selected via a cross-sequential design from two subject pools: a county clinic-based outpatient population (from medical records); and a community-based pool (from disability organizations and support groups, and general solicitation). A telephone screening was performed to confirm study eligibility and to collect personal background data.

Inclusion criteria for the subject pools varied by impairment group so as to capture epidemiological differences in disability trajectories. For polio, these criteria included a credible history of paralytic polio contracted in the United States, a minimum age of 37, and a duration of disability of 20 years. Rheumatoid arthritis criteria included a confirmed diagnosis, adult onset at 18 years or older, a minimum age of 30, and a post-diagnosis of 5 years. All potential subjects had to be living in the United States at time of onset, have some residual physical impairment at time of measurement and live within one hour of the medical center. See Table 2.

Table 2. Eligibility Criteria for AwD Survey Study by Impairment Group

Polio	Rheumatoid Arthritis
Reliable history of paralytic polio	Confirmed diagnosis for R.A.
At least 20 years post acute onset	Adult onset ≥18 years
Age ≥37	Age ≥30
Contracted polio in U.S.	≥5 years post diagnosis

A clinic-based pool was created by reviewing medical records from 1989 to 1994 and coded for study criteria characteristics using a structured data collection protocol. The community-based pool was created by recruiting volunteers from disability support groups and organizations, physician referrals, radio public service announcements and word of mouth among consumers. The community-based pool was created to compensate for biases in the clinic-based population with the size varying based on biases in the demographic and disability characteristics of each clinic sample (Campbell and Sheets, 1996). Table 3 is a summary of the recruitment and achieved samples.

Table 3. Overview of Sampling Framework and Achieved Sample

	Phase 1 Subject Recruitment		Phase 2 Sample Selection & Data Collection	
Sample	Clinic-based Subject Pool # eligible (# reviewed)	Community Subject Pool # eligible	Invited to Participate (By waves)	Achieved Sample
Post-Polio	632 (1,274)	325	348 (Clinic=177) (Community=171)	218
Rheumatoid Arthritis	375 (1,450)	130	388 (Clinic=277) (Community=111)	186
Totals	1007 (2,724)	455	736	404

[1]Number of waves sent out varied by sample: Polio = 11 waves; RA = 12 waves
(Source: M. Campbell, Aging with Disability Survey Study)

Each disability has unique epidemiological characteristics, thus stratification was used in this cross-sequential sampling framework. Both samples were stratified by chronological age to permit age comparisons. The unique Polio sample stratifying factors were gender and age of initial onset. The Rheumatoid Arthritis sample was stratified by race/ethnicity and duration of disability. As noted below in Table 4, RA has a disproportionate proportion of women because they develop RA three times more commonly than men.

Table 4. Cross-sequential Sampling Design for Achieved Study Sample

	Achieved Sample	
Polio	**Females**	**Males**
<64 years, early onset ≤10 years	20	36
<64 years, later onset ≥11 years	26	19
≥65 years, early onset ≤10 years	19	17
≥65 years, early onset ≥11 years	27	24
TOTAL	122	96
Rheumatoid Arthritis	**White**	**Non-White**
<64 years, duration 5-19 years	30	47
<64 years, duration ≥20 years	18	32
≥65 years, duration 5-19 years	10	8
≥65 years, duration ≥20 years	17	22
TOTAL	75	109

3. Sample Demographics

A summary of demographic characteristics appears in Table 5. Significant differences are found between the Polio and Rheumatoid Arthritis samples in age, gender, ethnicity, education, household income and current work status. Marital status had no significant differences. The Polio sample was predominantly white (87%), was more likely to have at least a high school diploma (83% vs. 55% for RA), reported a higher income level (51% had an income level of greater than $35,000 vs. 39% for RA). The Rheumatoid Arthritis sample was predominantly female (88% vs. 56% of Polio), Hispanic (47% vs. 5% of Polio), had less education (45% had less than a high school diploma), made less than $15,000 (34% for household income), and had never worked since disease onset (31% vs. 9% for Polio). The larger percentage of Hispanic subjects is reflects the race and ethnicity of the geographic location.

The county clinic is located in LA County which, in 2000, was 45% Hispanic and in a city where 58% of the population was Hispanic (City of Downey, 2000).

Table 5. Demographic Differences for Persons Aging with Polio or Rheumatoid Arthritis

Demographic Characteristics	p level	POLIO (*n*=218)	RA (*n*=186)
Current Age	.05	x= 61.0	x=58.5
Gender	.000		
Female		56%	88%
Male		44%	12%
Marital Status	NS		
Married/Cohabit		56%	50%
Divorced/Separated		20%	17%
Widow		13%	21%
Never Married		11%	12%
Race	.000		
White		87%	40%
Black		3%	9%
Hispanic		5%	47%
Asian & Other		3%	2%
Education	.001		
≤ High School		17%	45%
Some College		41%	37%
≥ College degree		42%	18%
	.01		
Household Income		19%	34%
≤$15,000		30%	27%
$15,001-$35,000		19%	13%
$35,001-$50,000		32%	26%
≥$50,001			
Current Work Status	.001		
Working (Full or Part-time)		33%	25%
Unemployed/Disabled		19%	16%
Retired/Homemaker/Volunteer		38%	28%
Never Worked since Onset		9%	31%

4. Data Collection

The interviews lasted from two to five hours, with most taking between two to three hours to conduct. Because the RA sample was 48% Hispanic, two of the interviewers were bilingual in English and Spanish. In the beginning of the interview, a "Participant Reminder Card" with important markers in the Polio and RA timelines was used so the respondent could refer to it during the interview. These were used in part to improve the quality of the retrospective information. Participant reminder card can be found in Appendix I.

B. Model Development for Present Analyses

Model development consisted of two parts: scale development and model testing. The first step was to develop measurement models using factor analysis to test a parsimonious set of latent variables for the three constructs of secondary conditions that have been discussed in the literature for persons aging with disability: 1) increases in disability-related symptoms; 2) increases in functional limitations; and 3) onset of chronic secondary conditions. The second step was to use the latent variables estimated from step 1 in an overall theoretical model exploring the predictive relationships in the disability trajectory. These can be found in Chapter III (Figures 3 & 4) polio and rheumatoid arthritis models respectively.) A detailed description of each variable included from the AwD Survey Study can be found in Appendix II.

1. Scale Development

Variables for increase in symptoms and increase in functional limitations were derived using change scores. Change, or difference, scores were calculated using variables measured by having subjects refer to a specific point in time in their disability history that was consistent with the underlying nature of their impairment (Campbell et al, 1999). This point in time is labeled "physical best" for polio and "reference period" for RA. The prior reference periods were

subtracted from companion variables measured at time of interview. These change variables were then used to derive three-level variables, mainly based on quantiles, for pain, fatigue, muscle weakness, joint stiffness, five basic activities of daily living (BADLs), five instrumental activities of daily living (IADLs), and six mobility variables. Scales were then constructed from the change variables in each category. This approach is utilized because the measures do not operate the same across the polio and RA groups (Campbell, 2012, email communication). Because of the nature of the disease, the RA group scores operate bi-directionally. Some subjects improved, while others declined. To use the traditional method of creating change scores after scales are constructed would eliminate the ability to compare the two populations as polio operates in one direction, showing decline (or as measured in these analyses, increase in symptoms and limitations). A mathematical difference score would potentially not capture the fluctuating aspects of RA in a single variable that is comparable across two populations (Campbell, 2012, email communication). Campbell et al (1999) have demonstrated the benefits in using change scores calculated in this way from these data.

Another issue is the significant variations in points in time which change was assessed. These varied significantly across the two impairment groups due to the differences in duration of disability and pace of change. Maynard et al. (1991), have demonstrated the utility of using objective self-reports that are tied to well-recognized benchmarks, such as an established reference period. Verbrugge and Yang (2002) note that the dynamic processes of disability and aging are best studied with longitudinal data whereas cross-sectional data creates a disability profile that is the "residue of prior dynamics (p.254)." However, she does support the use of cross-sectional data to study some aspects of the dynamic processes where questions have been incorporated regarding disability history.

Analyses conducted by Campbell (2012, personal correspondence) using this AwD data have found that the greater the amount of change people experience in areas such as function and symptoms, the more psychological adjustment is required to incorporate disability into their identify. Significant change in physical functioning and symptoms also has major implications for participation in social roles such as employment, family, and valued activities.

Increases in symptoms represent secondary conditions that occur as a direct result of the primary disabilities of polio and RA. Increases (change) in symptoms was measured on several three-level variables, calculated for pain, fatigue, muscle weakness (polio), and joint stiffness (rheumatoid arthritis).

Increases (change) in functional limitations originally had three domains with multiple variables in each. The first, increases in basic activities of daily living (BADL) limitations, included five items that address self-care and include toileting, bathing, dressing, transferring and eating. This domain was eliminated as the models were developed and will be discussed later in the paper. Increases in instrumental activities of daily living (IADL) limitations is the second domain. This consists of five variables that address more complex tasks such as shopping, meal preparation, medication management, etc. The third and final domain, increases in mobility limitations, consists of six variables that represent aspects of community and residential ambulation, climbing stairs and wheelchair use.

Chronic secondary conditions was originally called age-related chronic conditions and initially had two domains: mortality risk and morbidity. Modification of this construct will be addressed later in the paper. Mortality risk included nine diagnoses (cancer, COPD, kidney disease, liver disease, heart disease, hypertension, high cholesterol, diabetes, and stroke) of the most common mortality risk factors found in the National Health Interview Survey (NHIS)

(1994). Eleven morbidity diagnoses (amputation, asthma, dental, fracture, glaucoma, low vision, obesity, osteoporosis, skin breakdown, stomach problems and thyroid disease), also selected from the NHIS as well as the Surveillance Instrument of Secondary Conditions (Seekins et al., 1990), were included in the morbidity component of age-related chronic conditions. Mortality risk diagnoses represented those diagnoses that were the leading indicators of mortality at the time of the survey. Morbidity diagnoses were associated with chronic medical and physical conditions that represented complications of the primary disability and new onset of age-related diseases.

2. Predictive Model

The model for polio and rheumatoid arthritis is presented in Chapter 3 (Figure 3). There are three outcome variables: number of chronic secondary conditions, increases in functional limitations (IADL), and number of disability bed days in six months. The demographic/control variables consist of age, gender and education. Current work status is added to the demographic variables for the fully saturated model predicting number of disability bed days. The disability trajectory variables consist of duration, severity at onset and status at physical best for the polio sample. The RA sample trajectory variables are age at diagnosis, severity of onset and status at reference period. Increases in symptoms dimension consists of pain, fatigue, muscle weakness (polio) and joint stiffness (RA).

3. Final Analysis

Linear regression was performed to test the models for three outcome variables (number of chronic secondary conditions, increases in functional limitations and number of disability bed days in six months) in a theorized order for the polio and RA samples individually.

Regression analysis tests theoretically driven hypotheses by entering several predictor variables in an ordered sequence to determine the relative importance of a predictor by examining the unique contribution a predictor adds to the model above and beyond what can be accounted for by the other predictors (Petrocelli, 2003). The relationship between the predictor (or independent) variables on the dependent variable is evaluated by first entering control variables, followed by sets (or blocks) of predictor variables in a specified *a priori* order. Taken into account is the impact of a different set of predictor variables on the dependent variable while controlling for all the other predictors in the equation. At each stage, an additional predictor variable or variables are added to the model and ΔR^2 is calculated. A null-hypothesis test is undertaken to test whether the ΔR^2 is significantly different from zero. Of interest is the change in predictability associated with the predictor variables as they are entered in subsequent stages (Petrocelli, 2003).

V. RESULTS: SCALE DEVELOPMENT

A. Increases (Change) in Symptoms

Increase in symptoms was to be measured as one construct consisting of change, or difference, scores in self-reported pain, fatigue, muscle weakness (for the polio sample) and joint stiffness (for the RA sample). Since the increase in symptoms construct has only three variables in each subgroup, creation of an index was considered. Correlations were calculated to determine if there was enough common variance to combine the three variables into a single dimension index. Correlations among these variables were low (see Tables 6 and 7 below) and Cronbach's alphas (.490 for polio and .513 for RA) failed to meet the criterion for adequate internal consistency of .7 or greater. Thus these four variables (three for each sample) were treated as separate measures in the regression modeling.

Table 6. Correlation Matrix for Change in Symptoms Variables For Polio Sample (n=218)

	Change in Muscle Weakness	Change in Fatigue	Change in Pain
Change in Muscle Weakness	1		
Change in Fatigue	.224**	1	
Change in Pain	.234**	.268**	1

**Correlation is significant at the 0.01 level (2-tailed).

Table 7. Correlation Matrix for Change in Symptoms Variables For Rheumatoid Arthritis (n=186)

	Change in Joint Stiffness	Change in Fatigue	Change in Pain
Change in Joint Stiffness	1		
Change in Fatigue	.261**	1	
Change in Pain	.218**	.460**	1

* Correlation is significant at the 0.01 level (2-tailed).

B. Increases (Change) in Functional Limitations

Increase in functional limitations construct was to be measured by three components: BADLs, IADLs and Mobility. Higher-level latent variables were analyzed by principal components analysis (PCA) and Varimax rotation with Kaiser Normalization.

1. Basic Activities of Daily Living

Five items were included in the basic activities of daily living component that measured change in bathing/showering, dressing/grooming, toileting, eating and transferring. Choice of these variables is informed by research studies in the field of health care and sociology (Katz, Ford, Moskowtiz, Jackson et al, 1963; Lawton and Brody, 1969; Kempen, Meyers and Powell, 1995; Thomas, Rockwood and McDowell 1998; Kane and Kane, 2000; Roehrig, Hoeffken, Pientka and Wedding, 2007). It is widely accepted that these items form a single scale with satisfactory psychometric properties.

Polio One factor was extracted. The eigenvalue (i.e., the variance of a linear function of the variables) of this factor (2.697) accounts for 54% of the variance. Table 8 displays the component values. A regression score was computed with the expectation that it would be used in the analysis.

Table 8. Polio Sample Factor Loadings for BADLs

	Component
	1
Change in bathing/showering	.791
Change in dressing/grooming	.798
Change in eating	.560
Change in toileting	.819
Change in transferring	.671

Extraction Method: Principal Component Analysis.

Rheumatoid Arthritis A single factor with an eigenvalue of 3.447 was extracted and accounted for 69% of the variance. See Table 9 for the loadings. A single regression score was computed for expected use in the subsequent analysis.

Table 9. RA Sample Factor Loadings for BADLs

	Component
	1
Change in bathing	.888
Change in dressing	.874
Change in eating	.772
Change in toileting	.867
Change in transferring	.741

Extraction Method: Principal Component Analysis.

2. Instrumental Activities of Daily Living

As with basic activities of daily living, IADLs are an important and widely used construct for measuring physical function. The items contained in this analysis are: change in ability to perform chores and/or light housework, meal preparation, medication management, use of the telephone, and shopping.

Table 10. Polio Sample Factor Loadings for IADLs

	Component	
	1	2
Change in chores/light house work	.795	.240
Change in meal preparation	.820	.023
Change in medication management	-.015	.914
Change in use of phone	.384	.598
Change in ability to shop	.838	.150

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

Table 11. Polio Sample One Factor Solution for IADLs

	Component
	1
Change in chores/light house work	.820
Change in meal preparation	.748
Change in medication management	.384
Change in use of phone	.606
Change in ability to shop	.820

Extraction Method: Principal Component Analysis.

Polio The PCA extracted two factors. Factor one, labeled "physical IADL" has an eigenvalue of 2.420 and explained 48% of the variance. These three items require greater physical effort to perform in addition to the cognitive aspects of the tasks. Factor two, labeled

"cognitive IADL" because of the two items' heavier cognitive burden has an eigenvalue of 1.008 and explains 20% of the variance. Table 10 displays the loadings for the two components.

An additional variable has now been added with the two factor results when the goal is to produce parsimonious models. More importantly, the RA sample loaded on one component (see Table 12 below) making it difficult to compare the two samples in the final analyses. Since the eigenvalue for factor two is 1.008, it just meets the criterion for extracting factors based on an eigenvalue of 1.000. Therefore, a Cronbach's alpha was calculated to determine whether these items would scale adequately. Cronbach's alpha was .723 making it an acceptable, if not optimal, option for a scale. A decision was made to compute a regression score based on one factor. Table 11 shows" the one factor solution.

Rheumatoid Arthritis PCA extracted one factor with an eigenvalue of 3.245 that explained 65% of common variance. A single regression score was computed for use in the final analysis. Table 12 displays the factor loadings.

Table 12. RA Sample Factor Loadings for IADLs

	Component
	1
Change in chores/light house work	.886
Change in meal preparation	.901
Change in medication management	.650
Change in use of phone	.706
Change in ability to shop	.852

Extraction Method: Principal Component Analysis.

3. Mobility

Six mobility items in the AwD Study were chosen to represent the many dimensions of moving, or "getting around," as opposed to walking. They are change in: getting around the

community; walking 2-3 blocks, getting around residence, walking across the room, climbing 10 stairs, and wheelchair use. Walking refers to the physical ability of moving one's lower extremities in a purposeful way. Walking is often used as a proxy for overall mobility (and thus for participation). In fact, one does not have to physically walk to be mobile. A person who does not have the ability to adequately use his/her legs may be able to fully participate in desired activities by using a wheelchair or scooter. Further, one may have the ability to walk, but may be fearful of falling for instance, and thus limit walking and the ability to fully participate in activities.

Polio Using PCA, two factors were extracted. Factor one, labeled "residential mobility," had an eigenvalue of 3.393 and accounted for 55% of variance. The second factor, labeled "community mobility," had an eigenvalue of 1.155 and accounts for 19% of the variance. See Table 13. As with the IADL items, the rheumatoid arthritis sample yielded one factor (see Table 15 below). Again, to reduce the number of variables, keep uniformity across samples and for conceptual reasons, a one-factor solution was desirable. The mobility dimension was not conceived strictly as ambulation. It is a continuum of mobility from residence to community and includes wheelchair as a mobility option. Therefore, a Cronbach's alpha was computed to determine if these items could be scaled together. Cronbach's alpha was .841, which places the items as a scale in the good range. A regression score was computed for inclusion in the final analysis. Table 14 details the one factor solution.

Table 13. Polio Sample Factor Loadings for Mobility

	Component	
	1	2
Change in W/C use	.708	.092
Change in getting around in community	.049	.920
Change in walking 2 - 3 blocks	.289	.887
Change in getting around residence	.856	.269
Change in walking across room	.906	.234
Change in climbing 10 stairs	.479	.639

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

Table 14. Polio Sample One Factor Solution for Mobility

	Component
	1
Change in W/C use	.585
Change in getting around in community	.657
Change in walking 2 - 3 blocks	.812
Change in getting around residence	.813
Change in walking across room	.826
Change in climbing 10 stairs	.785

Extraction Method: Principal Component Analysis.

Rheumatoid Arthritis One factor for the mobility items was extracted using PCA. Sixty-four percent of the variance was explained for an eigenvalue of 3.810 (Table 15). A regression score was calculated from this factor and was used in the final analysis.

Table 15. RA Factor Loadings for Sample Mobility

	Component
	1
Change in W/C use	.503
Change in getting around in community	.836
Change in walking 2-3 blocks	.900
Change in getting around residence	.800
Change in walking across room	.823
Change in climbing 10 stairs	.855

Extraction Method: Principal Component Analysis.

C. Number of Chronic Secondary Health Conditions

Originally, the construct of chronic secondary health conditions was conceptualized as a two-dimension construct, age-related chronic conditions. As discussed previously, these dimensions were mortality and morbidity diagnoses. The items included in each construct were collected at time of interview and are not change variables. Respondents were asked for each condition whether they had been diagnosed or treated for the condition by a doctor or other health care professional *since the onset of their disability*. The variables are dichotomous: yes or no.

For both mortality risk and morbidity, the combined samples of polio and rheumatoid arthritis were used to perform an exploratory factor analysis and derive scores for the purpose of data reduction. The samples were combined because subgroup analyses revealed that there was not enough statistical power to be confident in the findings if they were to be analyzed and used separately. Correlations were conducted on the nine mortality risk and eleven morbidity diagnoses using the whole sample. Low correlations prevented further analysis, specifically, exploratory factor analysis. Correlation coefficients for each are reported in Appendix III Tables

25 & 26. As a result, mortality risk and morbidity diagnoses were combined and a summing strategy was employed.

The chronic secondary conditions variable was constructed by identifying dichotomous (yes/no) items from both the mortality risk and morbidity categories previously identified from the NHIS. Three conditional items were constructed: respiratory, arthritis, and gastrointestinal (GI). The respiratory item was given a "yes" score of 1 if a subject had emphysema/COPD and/or respiratory insufficiency. Likewise, arthritis was given a "yes" score of 1 if the subject had osteoarthritis and/or osteoporosis. Finally, the GI item was given a "yes" score of 1 if the subject had one or more of the following: ulcer, gastritis, colitis, irritable bowel syndrome or "other GI diagnosis." Other items in the chronic secondary conditions variable are: heart diagnosis, hypertension, stroke, high cholesterol, diabetes, cancer, skin breakdown, glaucoma, low vision, hearing loss, thyroid disease, kidney disease, liver disease, asthma and obesity. The above items were then summed.

D. Changes in Model Based on Scale Development Results

1. Increase in Functional Limitations

The construct of increase in functional limitations was broken apart. A decision was made to eliminate the BADL component. First, difficulty with BADLs generally occurs after difficulties in IADLs are seen and represent a lower level of functioning (Kempen, 1995). Both Polio and Rheumatoid Arthritis samples were community-based and this population typically represents a higher level of functioning. Secondly, the variability in the items could have been more favorable. Table 16 provides the frequencies for the BADL items. Thirdly, eliminating a variable contributed to a more parsimonious model.

Increase in mobility limitations was originally going to be analyzed with BADL and IADL. After dropping BADL, the order of mobility in the model was revisited and it's placement was separated from IADL. While still a component of functional limitations it has been placed after increase in symptoms and before chronic secondary conditions. This placement reflects the evidence that mobility is directly linked to disease characteristics, impairments and functional limitations (Guralnik, 2011).

Table 16. Frequencies for Change in Basic Activities of Daily Living Items for Polio and Rheumatoid Arthritis

Polio (n=218)	Bathing %	Dressing %	Eating %	Toileting %	Transferring %
No change	47	60	70	68	47
Changed a little	33	26	30	19	33
Changed a lot	20	14	18	13	20
RA (n=186)	Bathing %	Dressing %	Eating %	Toileting %	Transferring %
No change	65	58	67	70	65
Changed a little	19	22	21	18	19
Changed a lot	16	16	11	11	16

2. Chronic Secondary Conditions

As discussed above, chronic secondary conditions was originally called age-related chronic conditions and initially had two domains: mortality risk and morbidity.

The new variable was constructed by identifying chronic secondary conditions in current literature (The Lewin Group, 2010; Freid, Bernstein and Bush, 2012; Martin, Freedman, Schoeni et al., 2008; Schneider, O'Donnell and Dean, 2009). The name of the construct was changed from age-related chronic conditions to acknowledge secondary conditions' presence in the public health literature. An additional benefit of having one variable is that it supports a more parsimonious model.

3. Summary

A review of the factor scales for increase in functional limitations found both similarities and differences between polio and RA. The BADL scales were similar for the two subgroups. The loadings of the IADL one factor scales were similar to RA except for change in medication management (.384 compared to .650). This lower value may be related to the number of medications that required management and the fluctuating character of RA. The RA sample took 15% more prescription medications than the polio sample. Comparing mobility, the one factor solutions are extremely close. This speaks to the essential features of mobility. There is more consistency in performance of all the items as opposed to how one dresses oneself or prepares meals.

VI. RESULTS: MODEL TESTING

Higher rates of most health problems compared to same-age cohorts in the general population are reported by persons aging with physical disability. Using these AwD data, Campbell, Sheets and Strong (1999) compared frequencies of chronic conditions in a combined sample of individuals aging with polio, RA and stroke to population estimates of age-matched cohorts (45 – 64 year olds) from the 1994 National Health Interview Survey. Out of 17 comparable chronic conditions, higher significant rates of chronic conditions were reported for all but two conditions, hearing loss and heart disease.

To examine frequencies between NHIS population estimates and these AwD subsamples of polio and RA, Fisher's exact test was used to test whether there were differences in the frequencies of chronic secondary conditions between the AwD polio subsample and NHIS estimates, and AwD RA subsample and NHIS estimates for the same cohorts in the population at large using the 1994 National Health Interview Survey (NHIS). Chronic secondary conditions were used where there were comparable data in the NHIS. Two age cohorts were examined: 45 – 64 year olds, and 65 years old and greater. Table 17 shows results of the frequencies between each subsample and NHIS estimate.

The younger middle-aged cohort of persons aging with physical disabilities reported higher rates of chronic secondary conditions. Those with RA in the younger cohort reported higher rates than those with polio in all categories but three, hearing loss, heart disease and stroke. The older 65+ cohort aging with physical disability reported higher rates as well, but not in as many conditions. Those with RA reported higher rates in three chronic secondary conditions. Polio reported two conditions. There is evidence of "accelerated aging" in these data when compared with the NHIS estimates of the general population.

Table 17. Comparisons of Frequencies of Selected Chronic Health Conditions between Aging with Disability (AwD) Samples of Polio and Rheumatoid Arthritis and Age-Matched 45 – 64 year old and 65+ year old Cohorts from the 1994 National Health Interview Survey (NHIS)

	AGE 45 – 64 COHORT			AGE 65+ COHORT		
Secondary Health Conditions	**Polio n=124 %**	**RA n=102 %**	**NHIS Estimate %**	**Polio n=87 %**	**RA n=58 %**	**NHIS Estimate %**
Sensory Impairments						
Low vision	21**	31***	5	12	31***	8
Glaucoma	2	7†	1	8	7	6
Hearing Loss	15	16	14	24	50**	29
Circulatory Disorders						
Heart Disease	18	8	14	28	28	33
Hypertension	40**	42**	22	54*	47	36
Stroke	7	1	2	4	10	6
Endocrine Disorders						
Diabetes	15†	16*	6	6	28**	10
Kidney Disease	7	10*	2	4	7	2
Respiratory Disorders						
Asthma	15*	18**	5	15*	10	5
Emphysema/COPD	6	11**	1	7	2	5

†***p*<.1 **p*<.05 ***p*<.01 ****p*<.001 (p-values correspond to two-tailed Fisher's Exact Test for 2x2 table)

A. Interrelationships Among Components

1. Polio

For those aging with polio, increases in mobility limitations will be more strongly related to increases in functional limitations than to the number of chronic secondary health conditions, controlling for demographic and disability characteristics.

For those aging with polio, increases in mobility limitations predicts both increases in functional limitations ($p<.001$) and the number of chronic secondary health conditions ($p<.001$).

Consistent with this hypothesis, increases in mobility limitations, is a stronger predictor of increases in functional limitations (beta = .537) than of the number of chronic secondary health conditions (beta = .282). Results are contained in the final models in Table 19 (model 4) and Table 21 (model 5).

2. Rheumatoid Arthritis

For those aging with rheumatoid arthritis, increases in symptoms (fatigue, pain and joint stiffness) will be more strongly related to increases in functional limitations than to the number of chronic secondary health conditions, controlling for demographic and disability characteristics.

The empirical evidence provides mixed support for this hypothesis. For those aging with rheumatoid arthritis, increases in fatigue ($p<.05$) and increases in pain ($p<.05$) predicted increase functional limitations, but joint stiffness did not. Neither increases in pain, fatigue or joint stiffness predicted number of chronic secondary health conditions. Thus two of the three hypothesized predictors, increases in fatigue and pain, are more strongly related to increases in functional limitations than to the number of chronic secondary health conditions for persons aging with rheumatoid arthritis. Results are contained in the final models in Table 20 (model 4) and Table 22 (model 5).

B. Unique Disability Characteristics

1. Polio

For those aging with polio, disability trajectory indicators (severity of initial onset, duration of disability and status at physical best) will be more strongly related to increases in functional limitations than to the number of chronic secondary health conditions controlling for demographic characteristics for individuals aging with polio.

None of the three trajectory indicators for polio, severity at onset, duration, and status at physical best, predicted functional limitations or number of chronic secondary health conditions. Thus, this hypothesis for polio was not supported. Results can be found in the final models in Table 19 (model 4) and Table 21 (model 5).

2. Rheumatoid Arthritis

For those aging with rheumatoid arthritis, disability trajectory indicators (severity of initial onset, age at diagnosis and status at reference period) will be more strongly related to the number of chronic secondary health conditions than to increases in functional limitations controlling for demographic characteristics for individuals aging with rheumatoid arthritis.

None of the three trajectory variables for rheumatoid arthritis (severity of onset, age at diagnosis, and status at reference period) predicting the number of chronic secondary health conditions were significant. Of the three predictors, only status at reference period ($p<.05$) predicted increases in functional limitations. Thus hypothesis was not supported for rheumatoid

arthritis. Detailed results appear in the final models in Table 20 (model 4) and Table 22 (model 5).

C. Disability Bed Days

1. Polio

For individuals aging with polio, increases in symptoms (pain, fatigue, muscle weakness), increases in mobility limitations and increases in functional limitations will be stronger predictors of the number of disability bed days in the last six months than will the number of chronic secondary health conditions, controlling for demographic and disability characteristics.

For those aging with polio, increase in fatigue ($p<.05$) and increases in functional limitations ($p<.001$) predicted the number disability bed days in the last six months whereas mobility limitations did not. The number of chronic secondary health conditions did not predict the number of disability bed days. Hence there was partial support for the polio subsample for this hypothesis. See the final model (model 6) in Table 23 for details.

2. Rheumatoid Arthritis

For individuals aging with rheumatoid arthritis, the number of chronic secondary health conditions will be a stronger predictor of the number of disability bed days in the last six months than will increases in symptoms (pain, fatigue, joint stiffness) increases in mobility limitations and increases in functional limitations, controlling for demographic and disability characteristics.

For individuals aging with rheumatoid arthritis, the number of chronic secondary health conditions ($p<.001$) predicted the number of disability bed days in the last six months. Increases in symptoms and increases in mobility limitations did not predict the number of disability bed days in the last six months, but increases in functional limitations ($p<.05$) did. For individuals with rheumatoid arthritis, partial support is found for this hypothesis. See the final model (model 6) in Table 24 for detailed results.

D. Compare Disability Group Differences: Pooled Sample Hypothesis

Based on measures available for those aging with polio and also those aging with rheumatoid arthritis, relationships between predictors and outcomes (controlling for demographic variables) will not consistently be stronger for either disability group. This hypothesis applies to the common predictors of increases in chronic secondary health conditions (three predictors), increases in functional limitations (four predictors), and the number of disability bed days in six months (five predictors).

The prior six within-sample hypotheses addressed three domains (one in each domain for each subsample). As a follow-up to the polio and RA hypotheses, a hypothesis is presented involving tests of interaction to determine the significance of differences between the models for the two disability groups. This hypothesis offers a partial test of whether data on the two disability subsamples could be pooled. There were, however, certain differences between the measures used to assess the relationships tested in the within-sample polio and RA hypotheses and the measures used in testing this between-sample hypothesis: the variables measuring the disability trajectory differed for the two samples and were omitted; and the between-sample

hypothesis tested outcomes one at a time, whereas the within-sample hypotheses included comparisons involving more than one outcome.

1. Interactions Between Disability Group and The Number Of Chronic Secondary Health Conditions

An analysis examined differences between the two disability groups in the strength of predictors. Comparisons between the polio and RA subsamples were conducted by pooling the subsamples and testing for interaction. In separate regressions for each predictor, that is, the interaction between the predictor and a dichotomous measure of disability type (i.e., subsample) was tested. Also included in the regressions for this analysis were three control variables (age at interview, gender and education). The three disability trajectory variables for each sample (polio: duration, severity of initial onset and status at physical best; RA: age at diagnosis, severity of initial onset and status at reference period) were omitted because they were not equivalent across samples.

In testing for group differences for predictors of the number of chronic secondary health conditions, the samples had three predictors common to both samples: increases in pain, increases in fatigue, and increases in mobility. None of the three predictors generated a significant interaction with disability group. The analyses produced no evidence that pain, fatigue or mobility was a stronger predictor of chronic secondary health conditions for one disability group or the other. Detailed results on interaction are summarized in Table 18.

Table 18. Summary of Predictor Interaction Tests for Three Outcome Measures for the Pooled Sample (N=404)

Interaction (outcome x predictor) w/sample	Unstandardized Coefficients B	SE	Sig.
Chronic Secondary Conditions x			
Increase in Pain	.271	.347	.435
Increase in Fatigue	-.117	.354	.740
Increase in Functional Limitations x			
Increase in Pain	.520	.152	.001
Increase in Pain (w/additional controls)	.278	.121	.022
Increase in Fatigue	.494	.158	.002
Increase in Fatigue (w/additional controls)	.185	.125	.140
Increase in Mobility Limitations	.034	.076	.655
Number of Chronic Secondary Conditions	-.033	.045	.458
Number of Disability Bed Days in 6 months x			
Increase in Pain	.012	.128	.923
Increase in Fatigue	-.026	.130	.842
Increase in Mobility Limitations	-.005	.077	.951
Number of Chronic Secondary Conditions	.055	.035	.119
Increases in Functional Limitations	-.047	.073	.519

Table 19. Summary of Regression Analysis for Variables Predicting Number of Chronic Secondary Health Conditions for Polio (N=218)

	Model 1 (n=203)			Model 2 (n=203)			Model 3 (n=203)			Model 4 (n=203)		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Age at Interview	.012	.014	.057	.013	.016	.061	.015	.016	.072	.004	.016	.018
Female	-.976	.305	-.221**	-1.025	.308	-.232**	-.969	.305	-.220**	-1.089	.297	-.247***
Education	-.332	.211	-.108	-.309	.214	-.101	-.286	.212	-.093	-.343	.205	-.112
Severity of Initial Onset				.154	.221	.054	.076	.223	.027	.143	.217	.050
Duration				.040	.238	.013	.028	.236	.009	.082	.229	.027
Status at Physical Best				.187	.218	.067	.238	.221	.085	.189	.215	.068
Increases in Fatigue							.370	.247	.108	.281	.240	.082
Increases in Pain							-.132	.240	-.040	-.401	.243	-.120
Increases in Muscle Weakness							.584	.282	.149*	.305	.283	.078
Increases in Mobility Limitations										.614	.162	.282***
F		4.895			2.804			2.808			4.141	
R^2		.068			.079			.115			.177	
F for change in R^2		4.895**			.732			2.673*			14.397***	

†*p*<.1 *p<.05 **p<.01 ***p<.001; B=unstandardized coefficient; *β*=standardized coefficient

Table 20. Summary of Regression Analysis for Variables Predicting Chronic Secondary Health Conditions for Rheumatoid Arthritis (N=186)

	Model 1 (n=182)			Model 2 (n=182)			Model 3 (n=182)			Model 4 (n=182)		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Age at Interview	.063	.013	.341***	.070	.017	.379***	.068	.017	.369***	.067	.017	.366***
Female	-.797	.481	-.115	-.788	.483	-.114	-.701	.485	-.101	-.662	.489	-.096
Education	-.367	.204	-.125	-.357	.206	-.121	-.290	.210	-.099	-.280	.211	-.095
Age at Diagnosis				-.012	.017	-.061	-.013	.017	-.069	-.013	.017	-.070
Severity of Initial Onset				-.149	.207	-.052	-.193	.209	-.068	-.195	.209	-.068
Status at Reference Period				-.198	.171	-.082	-.054	.191	-.022	-.039	.193	-.016
Increases in Fatigue							.293	.325	.075	.240	.335	.061
Increases in Pain							.166	.315	.043	.096	.332	.025
Increases in Joint Stiffness							.195	.168	.086	.167	.173	.173
Increases in Mobility Limitations										.133	.197	.060
F		10.225			5.487			4.090			3.715	
R^2		.146			.158			.175			.178	
F for change in R^2		10.225***			.786			1.249			.454	

†*p*<.1 *p<.05 **p<.01 ***p<.001; B=unstandardized coefficient, SE B= standard error of B, *β*=standardized coefficient

2. Interactions Between Disability Group and Functional Limitations

In the testing for group differences for predictors of increases in functional limitations, there were four predictors, common to both samples: increase in pain, increase in fatigue, increase in mobility, and the number of chronic secondary conditions. As mentioned above, in the final subsample models of the hierarchical regressions, two of these four predictors, increases in mobility ($p<.001$) and chronic secondary conditions ($p<.05$), were positively and significantly related to increases in functional limitations for the polio subsample, and all four predictors, fatigue ($p<.05$), pain ($p<.05$), increases in mobility limitations ($p<.001$) and number of secondary conditions ($p<.05$) were positively and significantly related to increases in functional limitations for the RA subsample.

Included in the regressions for the differential effects analysis were the three control variables (i.e., age, gender and education), but not the three measures of disease trajectory, which differed for the two subsamples. Two of the four predictors generated a positive significant interaction with disability group: increases in pain ($p<.01$) and in fatigue ($p<.01$). These two regressions were rerun. Three of four common predictors (i.e., increase in pain, increase in fatigue, increase in mobility, number of chronic secondary conditions) were included as controls in addition to age, gender and education. The only significant interaction that remained was increases in pain (B for interaction term is .278; $p<.05$). One significant result at $p<.05$ among 12 tests of interaction is what would expect by chance alone, and this isolated significant result is likely to be a Type 1 error. Refer to Table 18 for tests of interaction between disability samples and each of the 12 predictors.

Table 21. Summary of Regression Analysis for Variables Predicting Increases in Functional Limitations for Polio (N=218)

	Model 1 (n=203)			Model 2 (n=203)			Model 3 (n=203)			Model 4 (n=203)			Model 5 (n=203)		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Age at Interview	-.002	.007	-.020	.000	.008	-.002	.005	.007	.050	-.006	.006	-.060	-.006	.006	-.063
Female	-.182	.143	-.090	-.183	.145	-.091	-.130	.131	-.065	-.243	.109	-.121*	-.171	.111	-.085
Education	-.114	.099	-.082	-.212	.101	-.087	-.090	.091	-.064	-.144	.075	-.103†	-.121	.075	-.087
Severity of Initial Onset				.077	.104	.059	-.043	.096	-.033	.019	.079	.014	.009	.078	.007
Duration				-.049	.112	-.036	-.096	.102	-.069	-.045	.084	-.033	-.051	.083	-.037
Status at Physical Best				-.033	.103	-.026	.051	.095	.040	.005	.079	.004	-.007	.078	-.006
Increases in Fatigue							.193	.106	.124†	.110	.088	.070	.091	.087	.059
Increases in Pain							.244	.104	.161*	-.007	.089	-.005	.019	.088	.013
Increases in Muscle Weakness							.580	.122	.326***	.319	.104	.179**	.299	.102	.168**
Increases in Mobility Limitations										.574	.059	.578***	.534	.061	.537***
# Chronic Secondary Health Conditions													.066	.026	.145*
F		1.178			.708			5.728			17.008			16.485	
R^2		.017			.021			.210			.468			.486	
F for change in R^2		1.178			.252			15.456***			93.852***			6.451*	

†p<.1 $^{*}p$<.05 $^{**}p$<.01 $^{***}p$<.001; B=unstandardized coefficient; *β*=standardized coefficient

Table 22. Summary of Regression Analysis for Variables Predicting Increases in Functional Limitations for Rheumatoid Arthritis (N=186)

	Model 1 (n=182)			Model 2 (n=182)			Model 3 (n=182)			Model 4 (n=182)			Model 5 (n=182)		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Age at Interview	.004	.006	.054	.004	.007	.048	.001	.006	.011	-.001	.006	-.008	-.005	.006	-.056
Female	-.056	.235	-.018	-.070	.216	-.022	.066	.186	.021	.208	.164	.006	.247	.162	.079
Education	-.092	.100	-.069	-.111	.092	-.083	-.023	.081	-.017	.015	.071	.011	.032	.070	.024
Age at Diagnosis				.006	.008	.068	.002	.007	.022	.001	.006	.013	.002	.006	.022
Severity of Initial Onset				-.010	.093	-.008	-.053	.080	-.041	-.062	.070	-.048	-.051	.069	-.040
Status at Reference Period				-.453	.076	-.414***	-.186	.073	-.170*	-.131	.064	-.120*	-.129	.064	-.118*
Increases in Fatigue							.445	.125	.250***	.250	.112	.140*	.236	.111	.132*
Increases in Pain							.538	.121	.311***	.281	.111	.162*	.275	.110	.159*
Increases in Joint Stiffness							.168	.064	.163*	.064	.058	.062	.054	.057	.052
Increases in Mobility Limitations										.489	.066	.489***	.481	.065	.481***
# Chronic Secondary Health Conditions													.059	.025	.130*
F		.509			6.416			13.229			21.140			20.214	
R^2		.008			.179			.408			.551			.565	
F for change in R^2		.509			12.227***			22.214***			55.105***			5.464*	

†*p*<.1 *p<.05 **p<.01 ***p<.001; B=unstandardized coefficient; *β*=standardized coefficient

3. Interactions Between Disability Group and Disability Bed Days in Last Six Months

In the testing for group differences for predictors of the number of disability bed days in the last six months, there were five common predictors for both groups: increases in pain, increases in fatigue, increases in mobility limitations, number of secondary conditions, and increase in functional limitations. In the final subsample models of the hierarchical regressions, three of these five predictors were significantly related to number of disability bed days in the last six months for the polio subsample: increase in fatigue ($p<.05$), increase in mobility limitations (inverse relationship; $p<.1$) increase in functional limitations ($p<.001$). Two predictors were significant for the RA subsample: number of chronic secondary conditions ($p<.001$) and increase in functional limitations ($p<.05$).

Included in the regressions for the effect analysis were the three control variables (i.e., age, sex and education), but not the three measures of disease trajectory, which differed for the two polio and RA. None of the five predictors generated a significant interaction with disability group. Details can be found in Table 18.

Table 23. Summary of Regression Analysis for Variables Predicting the Number of Disability Bed Days in Six Months for Polio (N=218)

	Model 1 (n=201)			Model 2 (n=201)			Model 3 (n=201)		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Age at Interview	-.021	.006	-.273**	-.021	.007	-.267**	-.016	.006	-.211*
Female	-.106	.110	-.065	-.121	.111	-.074	-.081	.106	-.050
Education	-.260	.078	-.229**	-.264	.078	-.233**	-.261	.075	-.229**
Current Work Status	.095	.007	.098	.094	.077	.096	.042	.074	.043
Severity of Initial Onset				.152	.080	.143†	.099	.078	.093
Duration				.005	.086	.004	-.019	.082	-.017
Status at Physical Best				-.012	.079	.012	.009	.077	.009
Increases in Fatigue							.219	.086	.174*
Increases in Pain							.083	.084	.067
Increases in Muscle Weakness							.261	.099	.180**
Increases in Mobility Limitations									
# Chronic Secondary Health Conditions									
Increases in Functional Limitations									
F		6.757			4.494			5.611	
R^2		.121			.140			.227	
F for change in R^2		6.757***			1.418			7.213***	

†p<.1 *p<.05 **p<.01 ***p<.001; B=unstandardized coefficient; β=standardized coefficient

Table 23. cont'd Summary of Regression Analysis for Variables Predicting the Number of Disability Bed Days in Six Months for Polio (N=218)

	Model 4 (n=201)			Model 5 (n=201)			Model 6 (n=201)		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Age at Interview	-.017	.006	-.216*	-.016	.006	-.211*	-.014	.006	-.186*
Female	-.088	.107	-.054	-.043	.110	-.021	.013	.107	.008
Education	-.267	.076	-.235**	-.258	.075	-.227**	-.230	.073	-.202**
Current Work Status	.034	.075	.034	.010	.076	.010	-.003	.073	-.003
Severity of Initial Onset	.104	.078	.097	.096	.078	.090	.093	.075	.087
Duration	-.016	.083	-.014	-.021	.082	-.019	-.009	.079	-.008
Status at Physical Best	.006	.077	.005	-.004	.077	-.004	-.003	.074	-.003
Increases in Fatigue	.214	.086	.170*	.202	.086	.160*	.178	.083	.142*
Increases in Pain	.066	.088	.054	.085	.088	.069	.078	.085	.064
Increases in Muscle Weakness	.243	.103	.168*	.229	.102	.158*	.151	.101	.104
Increases in Mobility Limitations	.040	.060	.049	.016	.060	.019	-.124	.069	-.153†
# Chronic Secondary Health Conditions				.052	.027	.134	.037	.026	.096
Increases in Functional Limitations							.266	.069	.323***
F		5.128			5.078			6.174	
R^2		.229			.244			.299	
F for change in R^2		.450			3.729†			14.853***	

†*p*<.1 *p<.05 **p<.01 ***p<.001; B=unstandardized coefficient; *β*=standardized coefficient

Table 24. Summary of Regression Analysis for Variables Predicting the Number of Disability Bed Days in Six Months for Rheumatoid Arthritis (N=186)

	Model 1 (n=181)			Model 2 (n=181)			Model 3 (n=181)		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Age at Interview	-.009	.005	-.097	.002	.007	.028	.003	.007	.038
Female	-.353	.185	-.140†	-.324	.181	-.129†	-.310	.181	-.123†
Education	-.100	.079	-.106	-.084	.079	-.079	-.054	.080	-.050
Current Work Status	.090	.009	.077	.061	.097	.052	.068	.097	.058
Age at Diagnosis				-.014	.007	-.203*	-.016	.007	-.232*
Severity of Initial Onset				.134	.078	.129†	.123	.078	.119
Status at Reference Period				-.115	.064	-.131†	-.048	.071	-.055
Increases in Fatigue							.254	.122	.178*
Increases in Pain							.078	.118	.056
Increases in Joint Stiffness							-.039	.063	-.047
Increases in Mobility Limitations									
# Chronic Secondary Health Conditions									
Increases in Functional Limitations									
F		2.216			2.900			2.735	
R^2		.218			.104			.138	
F for change in R^2		2.216†			3.679*			2.208†	

$^{\dagger}p<.1$ $^{*}p<.05$ $^{**}p<.01$ $^{***}p<.001$; B=unstandardized coefficient; *β*=standardized coefficient

Table 24. cont'd Summary of Regression Analysis for Variables Predicting the Number of Disability Bed Days in Six Months for Rheumatoid Arthritis (N=186)

	Model 4 (n=181)			Model 5 (n=181)			Model 6 (n=181)		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Age at Interview	.002	.007	.035	-.006	.007	-.091	-.005	.007	-.076
Female	-.284	.182	-.113	-.209	.174	-.083	-.260	.174	-.104
Education	-.047	.080	-.044	-.015	.077	-.014	-.021	.075	-.020
Current Work Status	.065	.097	.056	.078	.092	.067	.076	.091	.065
Age at Diagnosis	-.017	.007	-.234*	-.014	.006	-.208*	-.015	.006	-.214*
Severity of Initial Onset	.121	.078	.118	.144	.074	.139†	.154	.073	.150*
Status at Reference Period	-.039	.072	-.044	-.034	.068	-.039	-.009	.068	-.009
Increases in Fatigue	.219	.125	.156†	.191	.119	.134	.142	.119	.100
Increases in Pain	.033	.124	.024	.019	.118	.014	-.038	.118	-.027
Increases in Joint Stiffness	-.057	.064	-.069	-.076	.061	-.092	-.087	.061	-.105
Increases in Mobility Limitations	.087	.073	.109	.071	.070	.088	-.028	.079	-.035
# Chronic Secondary Health Conditions				.117	.027	.322***	.104	.027	.288***
Increases in Functional Limitations							.206	.081	.258*
F		2.622			4.199			4.509	
R^2		.145			.230			.259	
F for change in R^2		1.423			18.569***			6.563*	

$^{\dagger}p<.1$ $^{*}p<.05$ $^{**}p<.01$ $^{***}p<.001$; B=unstandardized coefficient; β=standardized coefficient

VII. DISCUSSION

This study investigated samples from two disability groups, individuals aging with post-polio syndrome and rheumatoid arthritis. Six within-disability hypotheses and one between-disability hypothesis were tested using a framework that conceptualizes disability trajectories within a life course perspective. Exploratory factor analysis was used in scale development for three constructs of secondary conditions found in the hypotheses: increase in symptoms, number of chronic secondary health conditions and increase in functional limitations. Regression analysis was then conducted to test the six within-sample and one between-sample hypothesis using number of chronic secondary health conditions, increase in functional limitations and number of disability bed days in six months. The final models for polio and rheumatoid arthritis can be found in Figures 5 and 6 respectively.

A. Within-Sample Hypotheses

1. Polio

In the first hypothesis, increases in mobility predicted both functional limitations and the number of chronic secondary health conditions. The stronger predictor was increases in functional limitations as opposed to the number of chronic secondary health conditions thus providing support for the hypothesis. Clinical literature is considerable with respect to the disease course of post-polio syndrome. Individuals who had recovered from polio have found in mid-life that they are having difficulty with new muscle weakness, pain and fatigue. These symptoms result in difficulty with balance and ambulation, and can result in wheelchair use. Wheelchair use can affect functional activities. Research regarding mobility is repeatedly found in the literature, however, how pain, fatigue and new muscle weakness relates to mobility and

functional decline is inconsistent (Nollet, Beelen, Prins, de Visser et al., 1999; Stolwijk, Beelen, Lankhorst and Nollet, 2005).

The second hypothesis that the three trajectory variables (severity at onset, duration and status at physical best) would be more strongly related to increases in functional limitations than to the number of chronic secondary health conditions was not supported. Using the same dataset as this study, Sheets (1999) found similar results using disability trajectory variables for polio when looking at risk factors for decline in ADLs. The findings may be related to the way the disability trajectory component was constructed. A possibility would be to break apart the trajectory variables. Duration and severity of onset would stay together because the better represent the trajectory. The status at physical best would then follow in the model.

The findings of the third hypothesis were partially supported. Increases in mobility limitations did not predict the number of disability bed days in the last six months, but fatigue and increases in functional limitations did. The number of chronic secondary conditions was not significant as hypothesized. The finding that increases in mobility limitations did not predict the number of disability bed days might indicate that individuals who have mobility limitations have adapted to them. For example, mobility with an assistive device from a cane to a walker to a wheelchair accomplishes the goal of getting around. However basic mobility may be to overall function, it is sometimes the easier to solve. Functional activities such as preparing food or performing light housework can be complex, require many tasks/steps to complete, and can prove more difficult to ameliorate. If one is having more difficulty performing tasks such as these, it is likely that they are experiencing more secondary symptoms that require bed days.

2. Rheumatoid Arthritis

Two of the three hypotheses proposed for individuals aging with RA were partially

supported. The first hypothesis predicting that increases in symptoms would be more strongly related to increases in functional limitations than to the number of chronic secondary health conditions was partially supported. Increases in pain and increases in fatigue were significant, but not increases in joint stiffness, a characteristic symptom of rheumatoid arthritis. When increases in symptoms were first introduced in model 3 (Table 22), joint stiffness ($p<.05$) was significant. When increase in mobility limitations was added in model 4, the significance of increases in joint stiffness disappeared. Despite joints stiffness' importance as a symptom to RA's disease process, it has not shown up as a significant predictor, unlike pain and fatigue, in quantitative studies that have included symptoms. However, Lutze and Archenholtz's (2007) findings in a qualitative study demonstrate the impact joint stiffness has on individuals aging with rheumatoid arthritis. The fact that increases in pain and increases in fatigue and not increases in joint stiffness were found to be significant for increases in functional limitations has support in the literature (McKenna and Wright, 1985; Hallet, Thyberg, Hass et al., 2003; Strating, Van Schuur and Suurmeijer, 2007) taking into account differences in study design.

The hypothesis predicting that the trajectory variables (severity of initial onset, age at diagnosis, status at reference period) would be more strongly related to number of chronic secondary health conditions than to increases in functional limitations. There was no support for this hypothesis as there were no significant variables for either outcome of number of chronic secondary health conditions or increases in functional limitations. In a prospective study, Navarro-Cano, del Rincon, Pogosian et al. (2003) found that disease severity in individuals with RA was significantly related to mortality, independently of comorbid disease. Furthermore, severity, disease duration, age, sex and comorbidity predicted mortality. One explanation is that the chronic secondary health conditions variable was constructed of both mortality and morbidity

conditions. One reason for this was that combined subgroup analyses determined that there was not enough power to be analyzed separately. Secondly, it provided parsimony for causal modeling. This construct should be revisited with further analysis of individual mortality and morbidity secondary conditions.

The number of chronic secondary health conditions predicted disability bed days was partially supported. As hypothesized, however, increases in functional limitations also predicted disability bed day, when that wasn't the expectation. Increases in symptoms and increases in mobility did not predict disability bed days. One could reason that the significant finding of increases in functional limitations was the result of increases in symptoms. Pain and fatigue were found to predict functional limitations in the first hypothesis for RA and increases in those symptoms could be are contributing to the fluctuating nature of the disease process. However, as hypothesized, none of the symptoms of pain, fatigue or joint stiffness were significant. Fatigue ($p<.05$) was significant when it was first introduced in model 3 (Table 24). It's significance, however, attenuated in model 4 and disappeared in model 5.

B. Between-Sample Hypothesis: Strength of Predictor-Outcome Relationships

Similarities are examined across samples in predictor-outcome relationships when interactions are not present. The general pattern of positive relationships between predictor components (increase in symptoms, increase in mobility limitations, number of chronic secondary health conditions, and increase in functional limitations) and outcome (number of s, increase in functional limitations, and number of disability bed days) for both samples provided some evidence of the generality of the findings.

One hypothesis regarding sample differences in strength of predictors was tested with low-power tests of interaction to allow for statements of strength of effects. To avoid noise from

chance-based fluctuations in the data, a strategy for detecting interaction based on consistent patterns across predictors and outcomes was implemented. The absence of a credible pattern of interactions indicates that large replicable differences in predictor-outcome relationships between the samples are unlikely. More modest interaction effects, which may exist, could not be detected with the level of statistical power available.

1. Differences

Although there were significant predictor-outcome relationships for both disability groups, an analysis was required to examine the pattern of regression results for polio and RA to evaluate differential effect sizes across samples. Such tests of interaction typically have low power. To avoid treating chance-based fluctuations in the data as valid results, a strategy for detecting interaction based on consistent patterns across predictors and outcomes was implemented. Evidence of interaction is strongest under the five conditions that follow.

First, the differences between the effect sizes in the two disability samples for any given predictor and its outcome should be large. Coefficients for increase in pain and increase in fatigue for RA were larger than the corresponding polio coefficients. However, the increase in mobility and chronic secondary health conditions subsample coefficients for polio and RA are similar in size. This initial condition is not met.

Second, for any predictor, at least the larger of the coefficients in the two samples should be significant. This second condition was met for all four common predictors.

Third, the direction of the disability sample differences in predictor effect size should be consistent across predictors. In reviewing all four significant coefficients for RA, increases in mobility and number of chronic secondary health conditions are not directionally consistent with increase in pain and increase in fatigue. The RA increase in mobility and number of chronic

secondary health conditions coefficients are smaller than their polio counterparts while the RA increase in pain and increase in fatigue are larger than their polio counterparts. Therefore the third condition is not met.

Fourth, the significant predictors should have coefficients in the expected directions, either positive or negative. Because all significant predictor coefficients are positively related to the outcome as hypothesized, this fourth condition is met.

Fifth, the interaction term (predictor x outcome) in the regression that tests for interaction should be significant. Both increases in pain and increases in fatigue produced significant interactions with disability group based on increases in functional limitations as the outcome variable. When a conservative approach is taken by adding the three other common predictors as controls in separate regressions for increases in pain and increases in fatigue, only increase in pain remained significant. Given the expected rate of type I errors, it is unlikely that increase in pain would be a replicable predictor of the outcome, increase in functional limitations.

In summary, only two of the five conditions that render interaction effects credible were met. The absence of a credible pattern of interactions indicates that large replicable differences in predictor-outcome relationships between the disability groups are unlikely. More modest interaction effects may exist, but could not be detected with the level of statistical power available. Considering the pattern of results and the limited number of common predictors that could be tested, a reasonable conclusion would be that the predictors do not operate differently for the two disability groups. More reliable estimates of predictor effects (and generalizable conclusions) for the pooled sample would have been possible if all predictors had been measured in the same way for the two disability groups. This is an example of one of the challenges of cross disability research. The disability trajectory variables were measured differently between

the disability groups and are key variables to the underlying conceptual framework of aging with disability and life course perspective. The trajectory variables anchor the disability temporally and account for the differences between polio and RA with respect to their disease courses.

2. Similarities

When interaction is not present, examination of similarities across samples in predictor-outcome relationships is considered. The general pattern of positive relationships between predictor categories (increase in symptoms, increase in mobility limitations, number of chronic secondary health conditions, and increase in functional limitations) and outcome categories (number of chronic secondary health conditions, increase in functional limitations, number of disability bed days) for both samples provided some evidence of the generality of the findings.

Increase in mobility ($p<.001$ for both subsamples) is a significant predictor of increase in functional limitations for both the polio and RA samples. This is consistent with some findings from literature (Shimada, Sawyer, Harada, Kaneya, Nihei et al., 2010; Kingston, Collerton, Davies, Bond et al., 2012). Loss of mobility may be one variable that can operate across disabilities.

Chronic secondary health conditions ($p<.05$ for both samples) is a significant predictor of increase in functional limitations in both subsamples. Chronic secondary health conditions' placement in the Nagi/IOM framework is in the beginning of the model as secondary pathology. In this framework, it is not a direct effect to functional limitations as was in this analysis.

To summarize, two observations, common to both polio and RA, emerge from these data. First, increases in functional limitations predicts disability bed days. Second, increases in mobility, the number of chronic secondary health conditions, and increase is symptoms (muscle weakness for polio, and pain and fatigue for RA) predict increases in functional limitations.

Figures 5 and 6 contain the models for predicting chronic secondary health conditions, increases in function, and disability bed days. The beta coefficients and 95% confidence intervals are shown for the significant predictors.

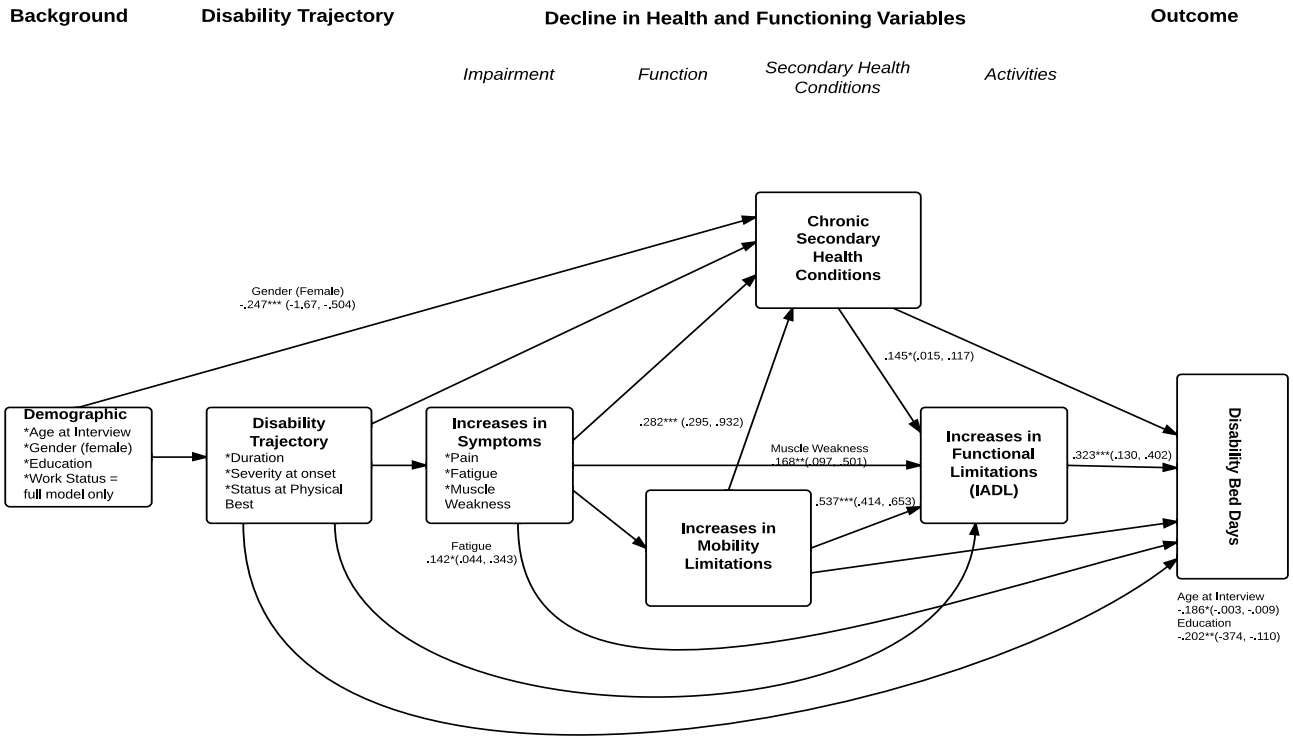

Figure 5. Polio Model for Predicting Chronic Secondary Health Conditions, Increases in Function and Disability Bed Days

Only Significant variables reported for beta coefficients & 95% confidence intervals
**p>.05 **p<.01 p<..001*

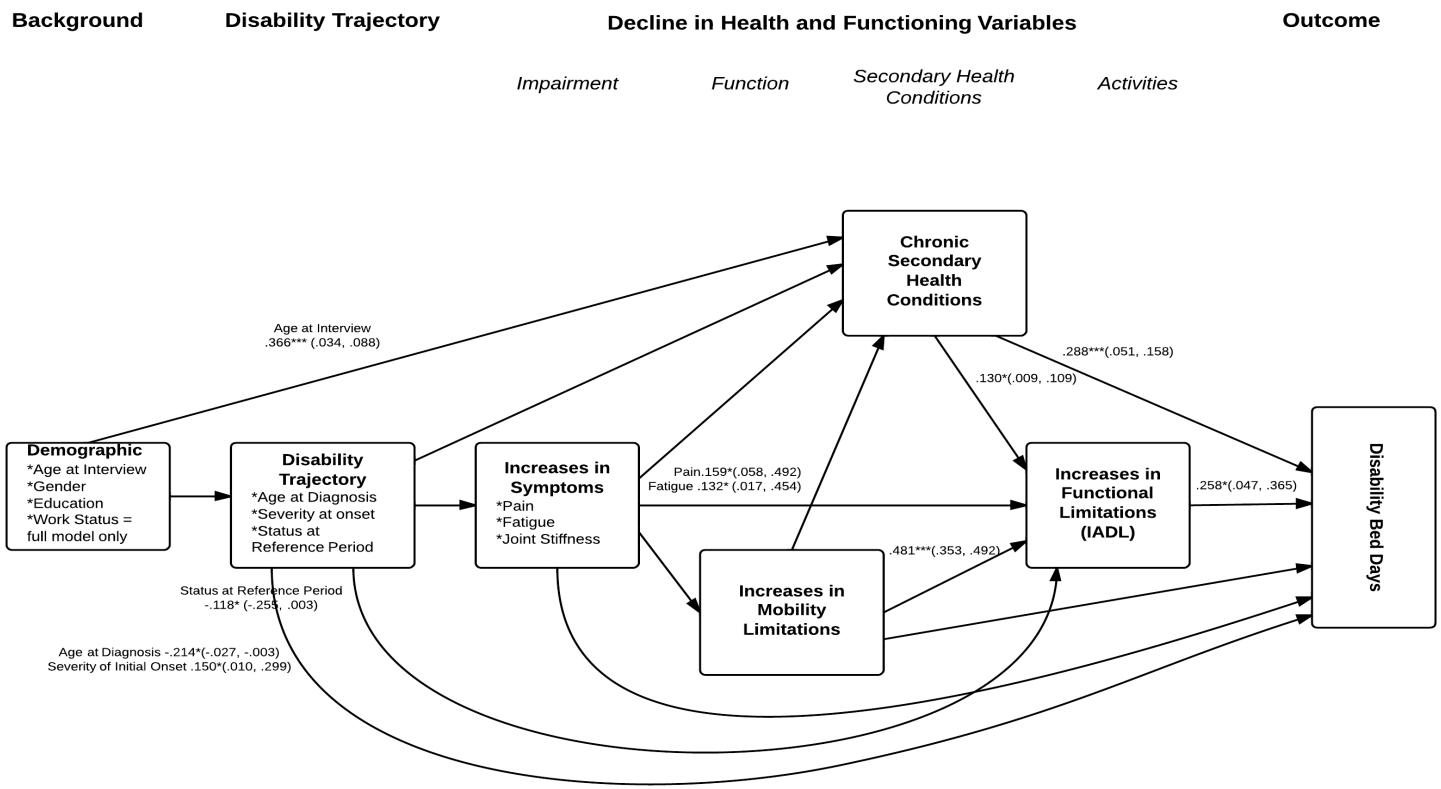

Figure 6. Rheumatoid Arthritis Model for Predicting Chronic Secondary Health Conditions, Increases in Function and Disability Bed Days

Only Significant variables reported for beta coefficients & 95% confidence intervals
**p>.05 **p<.01 p<..001*

C. Policy Implications

The within-sample analyses did yield partial results. The constructs that were significant for predicting number of disability bed days can give us some insight as to how policy could be considered. For instance, in the RA models, increases in functional limitations, the number of chronic secondary health conditions, and two of the three disability trajectory variables, age at diagnosis and severity at onset. All of these variables were positively associated with disability bed days except for age at diagnosis. Being younger when diagnosed with RA predicted more disability bed days. Backing up, one can then look at increases in functional limitations as the outcome. Increases in mobility limitations, number of chronic secondary health conditions, two symptoms (pain and fatigue) of the increases in symptoms component, and status at reference period all predict increases in functional limitations. Status at reference period negatively predicts functional limitations, therefore the more stable the disease process was at the last change in disease status, the more increases there were in functional limitations. Targeting those individuals who are younger, have more severity and who are having increases in symptoms (most likely pain and fatigue) for interventions before they are more likely to experience increases in secondary health conditions or increases in mobility limitations.

There are several ways to approach policy with the example above. On a macro scale, reducing the number of disability bed days has implications for the workplace (from both the employer and employee perspective), controlling health care costs, reducing the impact of lost income, as well as the psychological factors associated with not being able to function optimally. Looking at the interrelationships among the predictors could inform the public health, aging and disability communities as to where to intervene with programs on individual, community, institutional and governmental levels. Socioeconomic status, race and ethnicity also need to be

examined more closely as they can intensify the impact of these interrelationships. Finally, it can inform and educate those who are aging with, in this case, rheumatoid arthritis so that they can make the best choices for their circumstances.

D. Limitations

The first limitation of this study is its use of self-report that is at risk for memory bias. Self-report is easy and inexpensive, however, they risk bias and inaccuracy due to over and under reporting in items such as functional limitations. Other items, such as symptoms, are not subject to the same risk as they are intrinsically subjective. Only a respondent can assess severity of his or her pain.

With respect to diagnosis, there was no independent confirmation of being diagnosed or treated by a health care provider. Many individuals with polio were young when they were diagnosed and have relied on what others have told them for information about onset of and severity of their initial impairment.

There may be bias in accuracy of memory, especially when reporting changes over time, may result in exaggerated or diminished change. Memory is impacted by medication and individuals with disabilities are often on many medications, including those with RA. Symptoms such as pain and fatigue impact mood and could influence accuracy of reporting. In the future, introducing a limited number of performance measures such as pegboard test for fine motor and speed, picking up an object, lifting 10 pounds, gait speed, chair rise, and stair climb to the interview to supplement self-report would result in a more accurate assessment of limitations (Guralnik, 2011) and reduce the bias of the memory issues of self-report.

There are several measurement issues that are not optimal. The retrospective measurement of change limited to two points in time is subject to bias. It does not capture change

in severity of secondary conditions. The RA sample moves in and out of various levels of disability due to the fluctuating nature of the disease, thus this element of the disability trajectory is not illuminated. Due to the differences in disability trajectory, the measures of items across disabilities are problematic as they cannot be directly compared thus not all variables could be used.

Finally, subtraction-based change variables are sensitive to ceiling effects, that is, the most severe categories were less likely to change making interpretation of analyses difficult.

These data are nearly 20 years old. As discussed earlier in the dissertation, polio has been eradicated in much of the world. As of 1989, there was an estimated 1.6 million individuals in the United States aging with Polio. The present population cohorts may be experiencing aging with disability differently. Likewise, due to considerable advances in medication and surgery, those with RA will presumably "look" healthier than they were when these data were collected.

E. Contributions

This study attempted to go beyond univariate and bivariate analyses by addressing conceptual and analytic gaps in the secondary conditions literature using a causal model to demonstrate how the components of secondary conditions --- increases in symptoms, increases in mobility limitation, chronic secondary health condition and functional limitations --- work together to affect a public health outcome. It has been established from clinical observation and anecdotally that secondary conditions do not work in isolation; they interact with one another. These analyses are an initial attempt to change the dialogue in the literature from conceptual to analytical by using scale development to create measures of secondary conditions and then using those measures in a causal model to examine their interrelationships and predict a public health

policy outcome while controlling for background factors and disability trajectory which takes into account aging and the life course perspective.

F. Recommendations

1. Research Methods

Further research to examine the measurable dimensions of disability will assist in creating comparable measures so that all predictors may be included and used across disabilities. This holds true in investigating within-disability similarities and differences. Even within disabilities, it is difficult to make comparisons. In spinal cord injuries, for instance, individuals with the same level involvement may look very different in ADL limitations, for instance. An individual may have a complete or partial severation, or compression. The implications for all aspects of secondary conditions measured in this study are often quite striking. Scientific development is essential to advancing the field. Three areas need to be pursued: analytic method, study design and scale development.

Analytic methods that can establish causal relationships and investigate patterns of change need to be explored. Linear regression analysis may not be the correct analytical method for specification of this study's model. Other statistical methods, such as structural equation modeling may be more appropriate. Future research using longitudinal data, ideally panels, will likely improve study findings.

Addressing measurement and scale development is an essential consideration for better representing the multidimensional reality of what secondary conditions mean to aging with disability. There is a need to focus much more on how we construct composite analytic variables for components such as the ones in this study keeping parsimony in mind. It will be challenging and should be the first consideration in revising the study. A direction that one might take is to

"standardize" the types of secondary conditions before constructing and testing measurement models.

An additional consideration is the measurement of the outcome variable. This variable, number of disability bed days, may not have had the ability to capture any relationships between the constructs and outcome. Other public health policy outcome variables, such as health-related quality of life, number of physician visits, and participation, should also be tested with the same model.

2. Further Model Development

This model is a first step in going beyond the bivariate analyses found in the literature. The theory in the disability and secondary conditions field and how it relates to secondary conditions is developing. Contrasting this study's methods and model against others will be valuable going forward for refinement.

One conceptual model (Rimmer, Chen and Hsieh, 2011) that could be used to further develop and shape this study's model has two parts: the first is to systemically define secondary conditions and the second is to place secondary conditions within a clinical context that accounts for prevention interventions and policy implications. It does not look at interrelationships of secondary conditions as this model does. However, using Rimmer, Chen and Hsieh's hierarchical algorithm to define secondary conditions could prove beneficial. The algorithm takes a medical or nonmedical condition and attempts to standardize individual secondary conditions by considering the timing, association, prevalence, treatment complication and risk factor in that order. As the steps progress, the potential secondary condition can be bounced from the decision tree as a pre-existing condition, associated condition, comorbidity or treatment complication. Unlike other approaches where secondary conditions are defined in different ways,

with different components, and/or depending upon one's disciplinary perspective, Rimmer, Chen and Hsieh's approach attempts to be systematic and consistent.

Using the joint stiffness of rheumatoid arthritis, Rimmer, Chen and Hsieh's algorithm discussed above is illustrated. The *temporal* domain asks if the symptom occurs *after* the disability. In this case it does. Because of the slow development of the disease, it is also an indicator for diagnosing RA when two other symptoms are present: pain on movement and tenderness in the affected joints are present. The joint stiffness continues after onset. The next domain is *association*, which asks if there is a *direct* association with the etiology or progression of the disability. In this case, yes. The decision tree stops as joint stiffness is identified as an associated condition. Another potential condition of RA is poor pulmonary function. *Temporally*, it occurs *after* the disability. The *association* is not *direct* with the etiology or the progression of the disability. The next step asks if it is more *prevalent* in people with the disability. The 45 – 64 year old cohort of persons with RA were found to have significantly ($p<.01$) more COPD when compared to a national age-matched cohort (see Table 16). Whether it is a *treatment complication* is the fourth consideration. Although medication could result in some pulmonary symptoms, it is not always. The final consideration is whether it is a medical or health condition *risk factor*, which it is. COPD meets all of these criteria as a secondary condition to RA. There are potentially gray areas for many secondary conditions when considering any of these steps in the algorithm.

Within a research context, the algorithm for identifying secondary conditions has great potential. A caveat, however, is the potential for labor intensive data collection to determine (if needed) the entirety of each subject's secondary conditions and categorize them. Although not

perfect, this is the first systematic attempt to take the art out of secondary conditions and introduce more rigor and parsimony.

Rimmer, Chen and Hsieh's conceptual model is comprehensive, but complex. Its purpose is to understand the risk factors and consequences of secondary conditions in order to advance rehabilitation and health promotion research. Although this is not a conceptual model that addresses cross disability and aging, it does place secondary conditions within the clinical spectrum of medicine, rehabilitation, assistive technology, health promotion and public health. Starting with a primary disability, it identifies the onset and course of secondary conditions first via four non-modifiable antecedents: sociodemographic, pre-existing conditions, disability-related, and associated conditions.

Secondly, it progresses to personal and environmental modifiable risk factors. The third and final section provides a framework for identifying the outcomes of secondary conditions on both individual and societal levels. The model also acknowledges and provides for the range of prevention and intervention strategies from beginning to end of the model. Rimmer, Chen and Hsieh illustrate their conceptual model using the secondary condition of shoulder pain in an individual with spinal cord injury (SCI). They use this illustration clinically. The challenge to cross disability research is the adaptation their model using aggregated data in targeted areas to develop constructs for modeling the interrelationships of secondary conditions and AwD with respect to a policy, or societal level, outcome. What Rimmer, Chen and Hsieh do not address is the disability trajectory and life course context. They hint at it in their non-modifiable antecedents domain, however. The disability trajectory and life course perspective is what makes this study unique.

F. Conclusion

There has been little causal modeling using cross disability and aging data. This area of inquiry really isn't yet at the theoretical stage. To the extent there is a theory, it rests on two central constructs: secondary conditions and aging with disability. These constructs are linked because of the trajectory variables, but should be built upon separately as well. Secondary conditions are real, occur in high frequencies and result in accelerated aging. Definitions have varied from researcher to researcher and are now emerging from a lengthy period of research inactivity. These analyses are a first attempt at addressing this lack of analytical modeling of secondary conditions within a semi-theoretical framework.

The limited findings do not support what is known from bivariate analyses and the few attempts to model very limited aspects of the problem. Judgment must be withheld with respect to the hypotheses, however. The analyses did not yield enough predictive strength to make comparisons possible across subsamples. Likewise, in examining similarities, only general, descriptive statements could be made. The fact that relationships between the components and the outcome were not demonstrated could be a matter of scale development and/or statistical techniques. Secondary analysis can be problematic as one must work with predefined measures and limited ability to create measures tailored to the analyses. With that said, the use of secondary analysis is not entirely culpable. Although the same measures were used for most of the variables, the difficulty arose when comparing disability groups. The correct measures were used for disability trajectory and symptoms variables as they are what is unique to the two disability groups, however, this results in not being able to use identical measures throughout the entire models.

The subjective nature of disability is an immense challenge in cross disability research for comparability within disabilities, across disabilities, across national studies, and across international studies which can present its own set of cultural problems and language barriers. What has been learned from this study is where the science development is most needed.

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APPENDICES

APPENDIX I. PARTICIPANT REMINDER CARDS FOR POLIO AND RA

PARTICIPANT'S REMINDER CARD
"Important Markers in Polio Timeline"

Time of Initial Onset: **AGE:_____** **YEAR:_____** **_____DK**

Time of Initial Diagnosis: (if different) **AGE:_____** **YEAR:_____** **_____DK**

Period of "Physical Best"

AGES: **_____** **to** **_____** **_____DK** **_____N/A**

YEARS: **_____** **to** **_____** **_____DK** **_____N/A**

Other Important Dates (Optional):

Event: _____ **AGE:_____** **YEAR:_____**

Event: _____ **AGE:_____** **YEAR:_____**

PARTICIPANT'S REMINDER CARD
"Important Markers in Rheumatoid Arthritis Timeline"

When Diagnosed: **AGE:_____** **YEAR:_____** **_____DK**

Current Status: (check one)
_____Remission _____Good Period **_____Bad Period** **_____DK**

Timing of Most Recent "Remission" or "Good Period": **_____DK** **_____N/A**

AGE: **_____** **to** **_____**
MONTH: **_____** **to** **_____**
YEARS: **_____** **to** **_____**

Timing of Most Recent "Remission" or "Good Period": **_____DK** **_____N/A**

AGE: **_____** **to** **_____**
MONTH: **_____** **to** **_____**
YEARS: **_____** **to** **_____**

Other Important Dates (Optional):

Event: _____ **AGE:_____** **YEAR:_____**

Event: _____ **AGE:_____** **YEAR:_____**

APPENDIX II. DESCRIPTION OF VARIABLES USED OR DERIVED FROM AWD SURVEY INTERVIEWS

APPENDIX II

Description of Variables Used or Derived from AwD Survey Interviews (Campbell & Sheets, 1996)

			Applicable Sample		Variable Code
Construct	**Variable Name**	**Variable Content**	**Polio (=1)**	**RA (=2)**	
Background Characteristic/Control Variables					
	Age	Chronological age at time of interview	X	X	age
	Gender	1=female; 2=male	X	X	sex
	Education	1= high school; 2=some college or post high school; 3=college degree or higher	X	X	educ
	Current Work Status	1=yes; 2=no; 3=retired	X	X	cwkstat3
Disability Characteristics/Timing					
	Age at Dx	Age when rheumatoid arthritis was diagnosed		X	age_dx
	Duration	1=43 years or less; 2=44 – 52 years; 3=53 years or more	X		pdurat3d
	Severity of Initial Onset (Polio)	Number of limbs affected at onset: 0=0-1 limbs; 2= 2 limbs; 3=3-4 limbs	X		piimp53
	Status at Physical Best by Severity of Impairment - # limbs affected)	0=0-1; 2=2 limbs; 3=3-4 limbs	X		pbimp53
	Severity of Initial Onset (RA)	Number of joints affected at 1 year S/P onset: 1=0-2 joints; 2=3-5; 3=≥6		X	rijts3d
	Status of Disease Activity at Reference Period	1=remission; 2=good period; 3=bad period; 4=”5 years ago”		X	rperiod

			Applicable Sample		Variable Code
Construct	**Variable Name**	**Variable Content**	**Polio (=1)**	**RA (=2)**	
Increase (Change) in Symptoms since Physical Best (Polio) or Reference Period (RA)					
	Chang in severity of bodily pain: asked current status and reference period	1= none; 2= mild to moderate; 3= severe	X	X	C_Pain3L
	Change in severity of recurring fatigue: asked current status and reference period	1= none; 2 = mild to moderate; 3 = severe	X	X	C_Tired3L
	Change in severity of muscle weakness: asked current status and reference period	1= none; 2= a little to a fair amount; 3= a great deal	X		C_Mweak3L
	Change in Length of Joint Stiffness: asked current status and reference period	1= none; 2= a little to a fair amount; 3= a great deal		X	C_Jstiff3L
Increase (change) in Functional Limitations					
Function: Mobility	Change in walk 2-3 blocks in community: asked current status and reference period	1=none; 2=a little to a fair amount; 3=a great deal.	X	X	C_Cwalk3L
	Change in walk across room: asked current status and reference period	1=none; 2=a little to a fair amount; 3=a great deal	X	X	C_Rwalk3L
	Change in climb one flight of 10 stairs: asked current status and reference period	1=none; 2=a little to a fair amount; 3=a great deal	X	X	C_Stairs3L
	Change in get around community (by walking, using a scooter or wheelchair): asked current status and reference period	1=none; 2=a little to a fair amount; 3=a great deal	X	X	C_Cmobe3L

			Applicable Sample		Variable Code
Construct	**Variable Name**	**Variable Content**	**Polio (=1)**	**RA (=2)**	
Function: Mobility cont'd	Change in get around residence (with or without assistive devices or help from another person): asked current status and reference period	1=none; 2=a little to a fair amount; 3=a great deal	X	X	C_Rmobe3L
	Change in W/C use	1=no use; 2=part-time use; 3=full-time use	X	X	C_WC3DRC
	Mobility Scale	Regression Score	X		Polio_Mobility_Scale
	Mobility Scale	Single Factor		X	RA_Mobility_Scale
Function: IADL	Change in shopping (even if you have help from another person): asked current status and reference period.	1=no difficulty; 2=a little to a fair amount of difficulty; 3=a great deal of difficulty	X	X	Shop_C3
	Change in light housework/chores: asked current status and reference period	1=no difficulty; 2=a little to a fair amount of difficulty; 3=a great deal of difficulty.	X	X	Chores_C3
	Change in meal preparation (even if you have help): asked current status and at reference period	1=no difficulty; 2=a little difficulty to a fair amount of difficulty; 3=a great deal of difficulty	X	X	Meal_C3
	Change in using the telephone: asked current status and at reference period	1=no difficulty; 2=a little to a fair amount of difficulty; 3=a great deal of difficulty	X	X	Phone_C3
	Change in managing medications: asked current status and at reference period	1=no difficulty; 2=a little to a fair amount of difficulty; 3=a great deal of difficulty	X	X	Meds_C3
	IADL Scale	Regression Score	X		Polio_IADL_Scale
	IADL Scale	Single Factor		X	RA_IADL_Scale

			Applicable Sample		Variable Code
Construct	**Variable Name**	**Variable Content**	**Polio (=1)**	**RA (=2)**	
Function: BADL	Change in bathing/showering: asked current status and at reference period	1=no difficulty; 2=a little to a fair amount of difficulty; 3=a great deal of difficulty	X	X	C_Bath3L
	Change in dressing/grooming: asked current status and at reference period	1=no difficulty; 2=a little to a fair amount of difficulty; 3=a great deal of difficulty	X	X	C_Dress3L
	Change in toileting: asked current status and at reference period	1=no difficulty; 2=a little to a fair amount of difficulty; 3=a great deal of difficulty	X	X	CToilet3L
	Change in eating: asked current status and at reference period	1=no difficulty; 2=a little to a fair amount of difficulty; 3=a great deal of difficulty	X	X	C_Eat3L
	Change in transferring (even if you use assistive devices or have personal assistane): asked current status and at reference period	1=no difficulty; 2=a little to a fair amount of difficulty; 3=a great deal of difficulty	X	X	C_Trans3L
	BADL Scale	Single Factor	X		Polio_BADL_Scale
	BADL Scale	Single Factor		X	RA_BADL_Scale
Number of Chronic Secondary Health Conditions					
Chronic Secondary Health Conditions	Amputation, Arthritis (includes osteoporosis), Asthma, Cancer, Dental Problems, Diabetes, Fracture, Glaucoma, Hearing Loss, Heart Disease, High Cholesterol, Hypertension, Kidney Disease, Liver Disease, Low Vision, Obesity, Respiratory, Skin Breakdown, Gastrointestinal Disorders, Stroke, and Thyroid Disease	Each diagnosis: 0=no; 1=yes Variable created by summing total # of diagnoses for each case	X	X	MCC

			Applicable Sample		Variable Code
Construct	**Variable Name**	**Variable Content**	**Polio (=1)**	**RA (=2)**	
Dependent Variable					
	Disability Bed Days (the # of days spent in bed in the past 6 months)	1= 0 days; 2= 1 - 9 days; 3= greater than nine	X	X	disday3d

APPENDIX III. CORRELATIONS FOR MORBIDITY AND MORTALITY DIAGNOSES

Table 25. Correlations for Eleven Morbidity Diagnoses – Whole Sample (N=404)

	1	2	3	4	5	6	7	8	9	10	11
Amputation	1										
Asthma	-.074	1									
Dental	.095	.082	1								
Fracture	.079	.161**	.084	1							
Glaucoma	.087	.019	.041	.010	1						
Low Vision	.011	-.046	.258***	.065	.081	1					
Obesity	.058	.096	.057	.043	.016	.074	1				
Osteoporosis	-.004	.092	.209**	.161**	.057	.212**	.027	1			
Skin Breakdown	.081	.009	.031	.040	.059	.008	.148**	.070	1		
Stomach Disorder	-.023	.088	.215***	.045	.072	.099*	.060	.082	.178***	1	
Thyroid Disease	.012	.061	-.001	.045	.026	-.067	.042	.095	.065	.099*	1

Correlation is significant at *p<.05 **p<.01 ***p<.001 (2-tailed)

Table 26. Correlations for Eleven Mortality Risk Diagnoses – Whole Sample (N=404)

	1	2	3	4	5	6	7	8	9
Cancer	1								
Diabetes	.023	1							
High Cholesterol	.013	.127*	1						
COPD	.053	-.017	-.012	1					
Stroke	.086	.216***	.095	.070	1				
Heart Disease	.039	.067	.110*	.129**	.184***	1			
Hypertension	.072	.221***	.195***	.060	.079	.097	1		
Liver Disease	-.001	-.030	-.025	.060	.061	.104*	-.014	1	
Kidney Disease	-.062	-.034	-.014	.060	-.014	.048	-.009	.069	1

Correlation is significant at *p<.05 **p<.01 ***p<.001 (2-tailed)